



HOUSE OF LORDS

Select Committee on the Assisted Dying for the
Terminally Ill Bill

Assisted Dying for the Terminally Ill Bill [HL]

Volume I: Report

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HL Paper 86-I



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Committee on the Assisted Dying for the Terminally Ill Bill

The Committee was appointed to consider and report on the Assisted Dying for the Terminally Ill Bill presented on 24 November 2004. The Committee was appointed on 30 November 2004.

Membership

The Members of the Committee were:

The Earl of Arran
Lord Carlile of Berriew
Baroness Finlay of Llandaff
Baroness Hayman
Baroness Jay of Paddington
Lord Joffe
Lord Mackay of Clashfern (Chairman)
Lord McColl of Dulwich
Lord Patel
Bishop of St Albans
Lord Taverne
Baroness Thomas of Walliswood
Lord Turnberg

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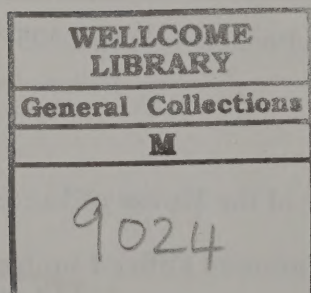
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NOTE:

The Report of the Committee is published in Volume I, HL Paper No 86-I. The Evidence of the Committee is published in Volume II, HL Paper No 86-II.

Reference in the text of the Report is as follows:

(Q) refers to a question in oral evidence (Volume II, HL Paper No 86-II)

ABSTRACT

The Assisted Dying for the Terminally Ill Bill seeks to legalise, for people who are terminally ill, who are mentally competent and who are suffering unbearably, medical assistance with suicide or, in cases where the person concerned would be physically incapable of taking the final action to end his or her life, voluntary euthanasia. We have examined both the principles underlying the Bill and its practical implications if it were to become law. We have also looked at the experience of other countries which have enacted legislation of this nature, and we have in addition made some analysis of public opinion in Britain on the subject.

The Bill is founded on the principle of personal autonomy. Its supporters believe that terminally ill people should have the right, subject to prescribed safeguards, to have medical assistance to die in the same way that patients, whether or not terminally ill, already have the right to refuse life-prolonging treatment. The Bill's opponents take the view that the two situations are not comparable, that it would be impossible to ensure that any safeguards were not abused and that the law should not be changed to permit intentional killing, whatever the motive.

On a practical level, we have heard conflicting views as to the likely effects of the Bill in giving benefit to some people or risking harm to others. It has been put to us, for example, that breaching the law on intentional killing would lead to a "slippery slope", whereby the terms of any law which were to be enacted would come to be applied more widely through incremental extensions of its provisions or elasticity in their interpretation and that experience of the 1967 Abortion Act and of voluntary euthanasia in The Netherlands provides evidence of this. On the other hand, it has been argued to us that the Bill contains an array of safeguards designed to prevent the emergence of a "slippery slope", that any relaxation would require further legislation, that the Bill is not comparable with the Abortion Act and that the evidence from Holland in fact provides reassurance.

We have also been told that the Bill would improve rather than (as its opponents have argued) damage doctor-patient relationships by allowing a more open and frank discussion of end-of-life concerns and that surveys have shown that the Dutch trust their doctors more than do people in many other European countries. On the other hand, we have been told that openness between doctors and patients, including discussion of end-of-life issues, has increased greatly in recent years and that the situation in The Netherlands is untypical in that most Dutch people remain with the same doctor for many years and know—and are known by—their doctors well. From the point of view of the medical profession, while some doctors are comfortable with what the Bill proposes and while the Royal Colleges of Physicians and General Practitioners adopted a neutral stance on the principle underlying the Bill, the General Medical Council wrote to us that "a change in the law to allow physician-assisted dying would have profound implications for the role and responsibilities of doctors and their relationships with patients".

It was also suggested to us, on the one hand, that with an appropriate "conscience clause" medical practitioners should have no more difficulty in implementing the Bill than have doctors in other countries which have enacted legislation of this nature and, on the other, that the composition of the medical and nursing professions in this country, with many doctors and nurses originating from non-European cultures, might pose serious problems for its implementation. And we

heard it suggested that the Bill would put some vulnerable groups of people, such as the disabled and the elderly, at risk but that opinion polls had suggested that majorities of people in these groups supported legislation along the lines of the Bill.

We visited three countries which have enacted different laws in this area. In the US State of Oregon medical assistance with suicide (but not direct action to end a patient's life) has been legal since 1997. The number of people availing themselves of the new law has been increasing, though by 2003 only 42 people (roughly one in 700 of those who died in Oregon in that year) were taking their own lives in this way every year. In The Netherlands, where a law permitting medical assistance with suicide or voluntary euthanasia was enacted in 2002 effectively codifying case law which had developed over the previous 30 years, approximately one in 40 deaths (most of them voluntary euthanasia) is attributable to this source, and there is evidence of around 1,000 additional deaths every year as the result of action by doctors for which no explicit request has been made. In Switzerland the law has allowed since 1942 assistance with suicide provided that the person giving such assistance is not motivated by self-serving ends. Assistance with suicide is not, however, seen in Switzerland as being confined to doctors; and, though as citizens doctors are able to give such assistance and any lethal prescription requires a doctor's signature, most assistance with suicide is provided by Swiss "suicide organisations".

Recent opinion polls suggest a high level of public support for a change in the law to allow terminally ill people to end their lives prematurely. Such polls have usually taken the form of simple Yes/No questions posed without an exploration of the surrounding context—for example, as to the availability and effectiveness of palliative care. Recent surveys also suggest that the attitudes of medical professionals are more ambivalent than public opinion as a whole and generally hostile to a change in the law. Our own postbag, which included over 14,000 letters and emails, suggests a narrow majority in favour of the Bill.

It is clear that Lord Joffe's Bill will be unable to make progress in the present session of Parliament due to shortage of time. We have therefore chosen to report now with an account of the evidence we have received (Chapters Two to Six) and with recommendations on how this matter should be handled hereafter (Chapter Seven) rather than ruling on the acceptability or otherwise of this particular Bill.

In brief, we recommend that:

- an early opportunity should be taken in the next session of Parliament for a debate on our report;
- if in the wake of such a debate a new bill should be introduced by a Member of the House, this should be referred, following a formal Second Reading, to a Committee of the whole House for detailed examination in the light of our report;
- in the event that such a bill should be brought forward, those responsible for framing it should give serious consideration to a number of key issues which have emerged during the course of our inquiry and which, we believe, lie at the heart of the debate on this subject.

The principal issues to which we wish to draw attention are as follows:

- It is clear to us from the evidence we have received that the demand for assisted suicide or voluntary euthanasia is particularly strong among determined individuals whose suffering derives more from the fact of their terminal illness than from its symptoms and who are unlikely to be deflected from their wish to end their lives by more or better palliative care. In any new bill which may be brought forward seeking to legalise assistance with suicide or voluntary euthanasia consideration should be given to focusing primarily on this group of people.

- It is also clear to us from the experience of other legislatures that there is a strong link between the scope of legislation in this area and its take-up by terminally ill people. In particular, where legislation is limited to assistance with suicide, the take-up rate is dramatically less than in places where voluntary euthanasia is also legalised. If therefore a new bill should be brought forward, it should distinguish clearly between assisted suicide and voluntary euthanasia and thereby give the House the opportunity to address these two courses of action separately.

- The present Bill is explicit in regard to the procedures which must be followed by a patient seeking assistance with suicide or voluntary euthanasia and those which must be followed after his or her death. But it is relatively silent about the procedures which a doctor must follow in giving effect to a patient's request once the latter has passed the various tests required. Any future bill should therefore make clear the actions which it would authorise a doctor to perform.

- While we support the principle that any future bill should contain robust safeguards, the detailed formulation of these should take account of the evidence which we have received. In particular, any definition of terminal illness should reflect the realities of clinical practice as regards prognosis; account should be taken of the need to identify clearly psychological or psychiatric disorder as part of any assessment of mental competence; and consideration should be given to including a test of "unrelievable" rather than "unbearable" suffering or distress.

- If any future bill is to claim credibly that palliative care is regarded as complementary rather than alternative to assisted suicide or voluntary euthanasia, consideration will need to be given to finding a means by which applicants can experience the effects of good palliative care rather than simply be informed of the existence of such treatment.

ASSISTED DYING FOR THE TERMINALLY ILL BILL [HL]

CHAPTER 1: INTRODUCTION

1. We were established following the decision of the House on 10 March 2004 to appoint a select committee to examine and report on the Assisted Dying for the Terminally Ill Bill [HL]. The terms of reference for a select committee on a bill are the bill itself. The committee's orders of reference are at Appendix 1. The committee has the power to decide whether the bill should proceed or not; and, if it is to proceed, the committee may amend the bill. In this opening chapter we set the scene for our inquiry, describe our *modus operandi* and outline the structure of our report. We also set out briefly, as a baseline for what follows, the present legal position regarding assisted dying, and we distinguish between the different terms which we use to refer to the various aspects of the subject.

Setting the Scene

2. This subject was last examined by Parliament in 1993/4 through the Select Committee on Medical Ethics. In its report¹ the committee concluded that there should be no change in the law on intentional killing, which it regarded as the cornerstone of law and social relationships, even in circumstances where the person concerned was terminally ill and had requested such action. The committee did not believe that it was possible to set secure limits on voluntary euthanasia and that "it would be next to impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law was not abused"². There was also concern that "vulnerable people—the elderly, lonely, sick or distressed—would feel pressure, whether real or imagined, to request early death" and that "the message which society sends to vulnerable and disadvantaged people should not, however obliquely, encourage them to seek death but should assure them of our care and support in life"³. The committee also drew attention to the increasing effectiveness of palliative care to relieve the distress of terminal illness in the great majority of cases.
3. Since the last select committee reported, there have been a number of developments. First, legislation to permit assisted suicide and/or voluntary euthanasia has been enacted in three countries overseas—the US State of Oregon (1997), The Netherlands (2002) and Belgium (2002). The legislation concerned varies from one country to another. In Oregon, for example, it permits only assistance with suicide, in Belgium is legalises only voluntary euthanasia, whereas in The Netherlands both practices are now permitted by law. Second, as Chapter Six of our report indicates, opinion polls continue to suggest that a majority of the public would support a change in the law and that such support has remained steady—and perhaps

¹ HL Paper 21

² HL Paper 21, Paragraph 238

³ HL Paper 21, Paragraph 239

increased slightly—during the last 10 years. Third, the ability of medicine as a whole to defeat life-threatening illnesses and of specialist palliative care to relieve the suffering of terminal illness has continued to improve. And there has been continued improvement in doctor/patient relationships in terms of open and frank discussion of diagnosis, prognosis and possible side-effects of treatment, reflecting an improvement in skills and ethics training, which are now taught in all undergraduate and some postgraduate clinical courses in the United Kingdom. There have also been instances during the last few years of United Kingdom citizens travelling to Switzerland in order to take advantage of that country's laws on assisted suicide.

4. In 2003 Lord Joffe introduced into Parliament his Patient (Assisted Dying) Bill, which included provisions for a competent adult who was suffering unbearably as the result of a terminal or serious, incurable and progressive illness to receive medical help to die at his or her own request. The Bill was given a Second Reading but did not proceed further⁴. On 10 March 2004 Lord Joffe introduced a second Bill (Assisted Dying for the Terminally Ill), the provisions of which were limited to terminally ill patients and which included a requirement for a discussion with applicants of the option of palliative care. In the light of these changes the Academy of Medical Royal Colleges adopted a neutral stance on the ethics of the Bill, while raising concerns on its provisions. The Bill was given a Second Reading, and it is this Bill which was referred to us for examination. The 2003/4 Parliamentary session ended while we were carrying out our remit. The Bill was re-introduced and given a formal Second Reading, and our remit was renewed (see Appendix 1).

Modus Operandi

5. We held our first meeting on 7 July 2004, after which we issued a call for written evidence to over 100 organisations with a known or presumed interest in the Bill (see Appendix 2). At the same time we invited contributions from individuals who wished to offer us their perspectives. Some 60 organisations answered our call for evidence, and we received over 14,000 letters or emails from individuals. While the great majority of these latter were from people briefly expressing either support for or opposition to the Bill, a significant minority came from persons who had either studied the subject of assisted dying or had experience of the operation of such legislation in other countries or were involved in professions (e.g. doctors and nurses) whose work would be closely affected if the Bill were to become law⁵.
6. We began taking oral evidence in September 2004. Since it was not practicable within the constraints of our timetable to hear evidence from other than a small number of those who had written to us, we focused our attention on three groups—the leading organisations advocating or resisting the Bill (the Voluntary Euthanasia Society and Right to Life, respectively); those organisations which represented the interests of people or professions who would be most directly affected if the Bill were to be enacted; and selected individuals with recognised knowledge or experience of assisted dying. We also visited the US State of Oregon, where legislation comparable in some respects to that envisaged in the Bill has been in force since 1997;

⁴ Lord Hansard 6 June 2003 Cols 1585-1690

⁵ A selection of these submissions will be published separately

The Netherlands, where there has been recent legislation with similar provisions to those envisaged in the Bill but where the legal status of voluntary euthanasia has been evolving over some 30 years; and Switzerland, where assisted suicide is permitted under yet different circumstances. We would like to express our gratitude to all those, both in this country and overseas, who took much time and trouble, in both written and oral evidence, to explain their views to us and to offer us the benefit of their experience. Without their help this report could not have been written. A full list of the organisations who gave us written or oral evidence and of the people who gave oral evidence to us in a personal capacity is shown at Appendix 3. We should like to thank also our Clerk, Mr Robert Preston, and our Specialist Advisers, Dr Calliope Farsides and Dr Richard Hillier, for their help with our task.

Structure of the Report

7. Though our terms of reference are the ADTI Bill itself, it is not possible to fulfil our remit simply by examining the text of the Bill. Much of the debate surrounding the issue of assisted dying is concerned with the principles underlying the Bill, in particular whether terminally-ill people should have the right to receive assistance to end their lives. Indeed, it is fair to say that the great majority of the letters and emails which we have received are concerned with the principles rather than with the detail of the Bill. To proceed to scrutinise the Bill without first examining these issues of principle might be seen as implying that the principle of assisted dying is taken as read and that all that matters is the detailed provisions of the Bill.
8. For this reason, after beginning our report (Chapter 2) with a description of the Bill, we proceed (Chapter 3) to examine the ethical principles underlying it. The central feature of the argument which has been put forward to us in support of the Bill is the principle of personal autonomy—that terminally-ill people should have the right, albeit limited by specified conditions, to decide when and under what circumstances they should die. On the other side of the debate, the principle of the sanctity (or inviolability) of human life has been put forward, stating that the law should not permit the deliberate taking of innocent life. We have felt it necessary to subject both these first principles to rigorous scrutiny at the outset of our report.
9. We then move on from theory to practice. In Chapter 4 we consider a range of issues which are concerned with the reality of assisted dying and which lie between the first principles and the detailed provisions of the Bill. As examples of these, we have examined the claim made by supporters of the Bill that euthanasia is happening in practice in Britain today and that terminally-ill people would be better protected if the practice were to be covered by statutory safeguards. We have examined also the argument put forward by the Bill's opponents that advances in palliative care in recent years have much reduced the need for such legislation and that, with further such advances in prospect, the proper answer to the suffering of the terminally-ill is better and more widely-available palliative care and support rather than assistance with suicide or voluntary euthanasia. We have also considered the argument—what is sometimes referred to as the “slippery slope”—that the enactment of Lord Joffe's Bill, or of one like it, would open the door to extension or abuse of assisted dying; and we have explored whether legalising such activities would, as some people believe, undermine

or, as others have suggested, improve the trust which exists between doctors and their patients.

10. In Chapter 5 we summarise the evidence we have received regarding the practice of assisted dying in places where this has been legalised. In doing so we have drawn heavily on the first-hand experience which we gained through short but intensive visits to the State of Oregon, to The Netherlands and to Switzerland; and we have summarised the current situation in Belgium.
11. While opinion has often been divided within our Committee on both the principles underlying the ADTI Bill and on its practical effects, there has been unanimity on one point at least—that, while the most careful account must be taken of expert evidence, at the end of the day the acceptability of assisted suicide or voluntary euthanasia is an issue for society to decide through its legislators in Parliament. We have therefore sought to establish a reliable picture of what the British people as a whole think about the subject. Though the timetable for our inquiry prevented us from conducting new research on the subject, we did commission a review of opinion surveys conducted over the last ten years, including both the population at large and specific groups of people (e.g. doctors and nurses) who would be directly affected if the Bill were to become law. In Chapter 6 we summarise the results of this review, and alongside this we set out our analysis of the response to the invitation issued in July 2004 to individuals to make their personal views known to us.
12. In Chapter 7 we present our conclusions. It is clear to us that, with a dissolution of Parliament likely in the near future, there would not be time for Lord Joffe's Bill to complete its various stages through both Houses even if there were to be consensus as to its acceptability. We have therefore decided that the most appropriate course of action for us in these circumstances is to present the evidence which we have received as a basis for a debate by the House early in the next session of Parliament and to recommend that, in the event that another bill should be introduced seeking to legalise assistance with suicide or voluntary euthanasia for terminally ill people, it should be referred after a formal Second Reading to a Committee of the whole House for examination. We set out also in Chapter Seven our thoughts on a number of key issues which have come to our attention in the course of this inquiry, and we would hope that these would be considered seriously by those who may frame any future bill on the subject.

The Present Legal Position

13. The Bill which we were set up to examine seeks to amend the present law, so it is necessary to be clear about what the present law is. We were helped in establishing this baseline, so to speak, for our inquiry by the Attorney-General, who kindly provided us with a memorandum⁶ summarising the law both on assisted suicide and voluntary euthanasia and on the refusal of medical treatment and food or fluids by individuals and who appeared before us to give oral evidence.
14. According to the Attorney-General, “the traditional attitude of the common law was to condemn suicide until the law was changed by the Suicide Act 1961. The 1961 Act provided: ‘the rule of law whereby it is a crime for a

⁶ See Volume II: Evidence, HL Paper 86-II, Page 578

person to commit suicide is hereby abrogated'. One result of the 1961 Act is that it is no longer a crime to attempt suicide. However, the 1961 Act continues to impose a considerable measure of responsibility upon persons other than the suicide or would-be suicide. The 1961 Act makes it a statutory crime to aid, abet, counsel or procure a suicide or attempted suicide and the offence carries a penalty of up to fourteen years' imprisonment"⁷.

15. "Deliberately taking the life of another person, whether that person is dying or not, constitutes the crime of murder. Accordingly, any doctor who practises mercy killing can be charged with murder if the facts can be clearly established"⁸. In oral evidence, however, the Attorney-General confirmed that it is not murder "where a doctor acts to do all that is proper and necessary to relieve pain with the incidental effect that this will shorten a patient's life" (Q 2073)—the so-called double-effect principle, of which we shall have more to say later in our report. Nor does the refusal of life-prolonging treatment by a patient constitute suicide, which in law requires a "positive act" (Q 2074); and a prisoner who refuses food does not in law "commit" suicide. By the same logic someone who does not take steps to force a person to eat or a patient to receive treatment is not regarded as aiding and abetting suicide (Q 2104).
16. This does not mean that anyone who is convicted of assisting suicide or "mercy killing" will automatically receive a prison sentence. Each case is considered on its merits by the Crown Prosecution Service in order to decide whether the evidence presented supports the charge and, if so, whether a prosecution would be in the public interest. Prosecutions are brought and, where those charged are found to be guilty, sentences of varying severity are imposed which are intended to reflect the circumstances of the case. The Director of Public Prosecutions does not however publish prosecution guidelines or criteria in such cases. When asked whether to do so might not make the legal position clearer, the Attorney General told us:

"The question was raised in the very sad case of Dianne Pretty whether or not the Director of Public Prosecutions could and should produce advance guidance as to the criteria that he would apply, but the view has been taken by the Director that he ought not to attempt to do that, that he should continue with the policy that he presently has, which is of reviewing the circumstances of any case presented to him after a police investigation, deciding on the circumstances of the case whether a prosecution should be brought or not. Part of the reasoning for that... is that it would be inappropriate... for him to issue a policy the effect of which was to say that 'I, the Director of Public Prosecutions, have decided to suspend or not to apply part of the law which Parliament has put in place and has not removed'" (Q 2094).
17. The effect of the ADTI Bill, were it to be enacted, would be to "make lawful that which currently would constitute the offence of murder or aiding and abetting suicide. If a person acted inconsistently with the provisions of the Act, he or she would remain liable to criminal penalties for that act" (Q 2078). The ADTI Bill seeks to remove criminal penalties from those who assist a competent and terminally-ill person who is suffering unbearably to

⁷ See Volume II: Evidence, HL Paper 86-II, Page 580

⁸ See Volume II: Evidence, HL Paper 86-II, Page 579

end his or her life or who end that person's life with his or her consent. Though the Bill provides for a terminally-ill person to request assistance to die, there is in fact nothing in law to prevent such a request being made now. The change in the law, were the Bill to be enacted, would lie in the freedom from prosecution of persons who acceded to such a request within the conditions set out.

Terminology

18. We have encountered in the course of our inquiry a number of terms used to describe the actions envisaged in the Bill and we have felt the need to agree on standard terminology in order to achieve precision in thinking. We have avoided, on the one hand, terms (such as "killing") which some find offensive and, on the other, phrases (such as "assisted dying") which others regard as either over-euphemistic or inaccurate (or both)⁹. Bearing in mind that in Lord Joffe's Bill there are two kinds of action envisaged in acceding to a request by a competent and informed person for assistance to end his or her life, we have used the term "assisted suicide" to mean providing someone with the means to end his or her own life and "voluntary euthanasia" to mean ending another person's life at his or her own request.

⁹ It has been suggested to us, for example, that assisting the dying is the role of doctors and nurses providing care, not of those who help people to take their own lives.

CHAPTER 2: THE BILL IN OUTLINE

19. This chapter sets out the detailed provisions of the ADTI Bill, drawing on the text of the Bill itself and on Lord Joffe's own comments on the Bill in the course of the oral evidence which he gave to us on 16 September 2004.

The Bill in Outline

20. The text of the Bill is at Appendix 4. Briefly, the Bill provides for a competent and terminally-ill person who has reached the age of majority and who is suffering unbearably to request either assisted suicide or voluntary euthanasia. It sets out the procedures to be followed in the event that such a request should be made, including an assessment by an attending physician that the patient's condition is such that he or she is likely to die of natural causes within a few months at most, that the patient is competent to make the request and that he or she is suffering unbearably. Given such an assessment and its confirmation by a consulting physician, the Bill provides for the requesting patient to sign a written declaration of intent and, if this has not been revoked within 14 days of the date on which the request was first made, to receive either the means to take his or her own life or, if the patient is physically unable to do that, to have his or her life ended through voluntary euthanasia.
21. The Bill provides a number of safeguards both for patients and for medical staff. These include the need for declarations to be independently witnessed, for patients requesting assisted suicide or voluntary euthanasia to have the opportunity to discuss the option of palliative care, for *ex post facto* examination of all deaths from this means by a monitoring commission, for doctors with a conscientious objection to be able to refer a requesting patient to another practitioner and for medical staff who comply with the terms of the Bill to be immune from both prosecution and breach of any professional oath or affirmation. The Bill also provides for terminally-ill patients to request and receive such pain-relief as they need to control the symptoms of their illness.

The Bill in More Detail

22. The Bill "is based on the principle of personal autonomy and patient choice, the right of each individual to decide for themselves how best he or she should lead their lives" (Q 70). For this reason the Bill applies only to competent patients. In Lord Joffe's words, "only a competent patient can make a decision in relation to his or her own life. For people who are mentally incompetent there needs to be, perhaps, a different system, but it cannot be based...on personal autonomy" (Q 108). The Bill does not require positive evidence of competence, simply that the attending physician shall "have no reason to believe that the patient is incompetent"¹⁰. The only requirement for proof of competence comes in Clause 8 of the Bill, which provides that, "if in the opinion of either the attending or the consulting physician a patient who wishes to make or has made a declaration may not be competent, the attending physician shall refer the patient to a psychiatrist for a psychiatric opinion" and that "no assistance to end that patient's life may

¹⁰ Clause 2(2)(b)

be given unless the psychiatrist has determined that the patient is not suffering from a psychiatric or psychological disorder causing impaired judgement, and that the patient is competent”¹¹.

23. Clause 8 suggests however that there could be a distinction to be drawn between incompetence, which is defined in the Bill as “not having the capacity to make an informed decision”¹², and psychiatric or psychological disorder (for example, depression), which might be temporary and treatable. This distinction was exposed in the course of oral evidence, when Lord Joffe expressed the view that “the key to it is really competence to make the particular very serious decision which has to be made, and we might not need anything about psychiatric illnesses, which I think muddies the position” (Q 151). Lord Joffe accepted however that this issue merited further exploration in the light of medical advice.
24. The Bill sets out¹³ the actions which must have been completed before a patient can make a declaration that he or she wishes either assisted suicide or voluntary euthanasia. The Bill makes clear¹⁴ that the request must originate from the patient. In oral evidence to us Lord Joffe’s stated that, “it is the patient who must initiate the request for assistance to die, not the physician, and no physician or other member of the medical team is entitled to assist the patient to die without the patient having initiated the request” (Q 70). Lord Joffe speculated subsequently(Q 131) that, in circumstances where a patient is suffering unbearably towards the end of his or her life and has not raised the subject, there might be a duty on the doctor to raise it as one of the available options, though he has since proposed an amendment designed to make clear that there should be no such duty. However, nothing in the Bill as it stands prohibits a doctor or nurse suggesting assisted suicide or voluntary euthanasia to a patient.
25. The Bill itself does not define precisely at which point a patient could be deemed to have made a request. In his oral evidence Lord Joffe recognized (Q 140) that some requests to die might not be seriously intended but might be rather a cry for help and that the Bill should be amended in such a way as to make clear that it is a formal request which would start the processes laid down in the Bill and that such a request should be made in writing and should be signed by the patient. Lord Joffe has proposed an amendment to cater for the situation where a patient cannot write.
26. The attending physician must decide that the patient is suffering from a terminal illness, which is defined in Clause 1 of the Bill as an illness which “is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will be likely to result in the patient’s death within a few months at most”. The attending physician must also have concluded that the requesting patient “is suffering unbearably as a result of that terminal illness”. Clause 1 defines “unbearable suffering” as “suffering whether by reason of pain or otherwise which the patient finds so severe as to be unacceptable”. It is clear from this, and from Lord Joffe’s evidence to the committee, that the definition of “unbearable suffering” is intended to be subjective—in Lord

¹¹ Clause 8

¹² Clause 1(2)

¹³ Clause 2 and 3

¹⁴ Clause 2(2)(a)

Joffe's words, "it is not what a doctor might say is the norm; it is that particular patient's suffering which is the subject matter of his decision" (Q 70). Lord Joffe does, however, add a proviso (Q 142)—that the doctor must assess "whether it is reasonable for the patient to have come to that conclusion". And, as Clause 1 makes clear, "unbearable suffering" might encompass suffering other than as the result of physical pain—what has been termed "existential suffering" (Q 70), including feelings of loss of dignity or self-worth—but does not include loss of competence resulting from suffering.

27. The requesting patient must be informed by the attending physician of his or her medical diagnosis, of the prognosis of the disease, of the process of assisted suicide or voluntary euthanasia and of the alternatives, "including, but not limited to, palliative care, care in a hospice and the control of pain"¹⁵. Clause 3 of the Bill places on the attending physician an obligation to ensure that "a specialist in palliative care who shall be a physician or a nurse has attended the patient to discuss the option of palliative care"¹⁶. Lord Joffe has made clear in oral evidence that such a consultation should not be construed as a guaranteed offer of palliative care. "All we can say is that, if the patient wants to have palliative care, he should ask for it and they should try to arrange it; but, if they do not or it is not possible, then the patient must make up his mind. That is what autonomy is about. It is about choosing between the options available to you rather than the ones you would like to have" (Q 148).
28. Once the attending physician has completed the various actions placed upon him in the Bill, and given that the patient has not withdrawn his or her application, the process must be repeated at the hands of a consulting physician in order to provide the safeguard of a second opinion. The Bill defines both the attending and consulting physicians in Clause 1. The consulting physician must be "practising in the National Health Service" and must be someone who is "qualified by speciality to make a professional diagnosis and prognosis regarding the patient's illness and who is independent of the attending physician". Lord Joffe explained in his oral evidence the thinking behind the requirements for NHS practice and for independence. "We do not want," he said, "a private practice to build up in relation to assisted dying where one or other consultant actually makes this the main service that they offer patients"; and "we do not want partnerships to be developed in terms that automatically a doctor within the attending physician's practice has an ongoing relationship with a particular consultant, to whom all patients are passed" (Q 70).
29. Clause 4 of the Bill sets out the requirements which must be met in the event that a patient, having completed the various steps required under Clauses 2 and 3, persists with his or her request and wishes to make a declaration. This must be witnessed by two individuals, of whom one must be a solicitor. The patient must be "personally known" to each witness or must have "proved his identity", and it must "appear" to each witness that the patient is of sound mind and has made the declaration voluntarily. The solicitor must also be satisfied that the patient understands the effect of the declaration¹⁷. In answer to questions, Lord Joffe made clear that it was not intended that the

¹⁵ Clause 2(2)(e)(iv)

¹⁶ Clause 3(1)

¹⁷ Clause 4(2)-(4)

witnesses should have in-depth knowledge of the patient. “We are asking them to sign a document saying that they were there at that particular time and that the patient appeared to them to be of sound mind and to have made the declaration voluntarily” (Q 88).

30. Clause 4 also precludes members of the medical care team and various categories of people who might have a vested interest in the patient’s death from acting as witnesses; and it provides that a declaration, once made, shall come into force after the requisite waiting period (defined in Clause 1 as 14 days, commencing on the date of the request) and shall remain in force (unless revoked) for six months. Revocation may be made at any time “whether orally or in any other manner without regard to [the patient’s] physical or mental state”¹⁸.
31. Clause 5 provides for the attending physician to act on the patient’s request for assisted suicide or voluntary euthanasia once the actions set out in Clauses 2 to 4 have been completed and provided that the patient has not revoked his declaration. The executive clauses of the Bill do not distinguish between providing the patient with the means to end his or her own life and ending the patient’s life for him or her. They are expressed in terms of “assisting the patient to die”, which is defined in Clause 1 as “the attending physician, at the patient’s request, either providing the patient with the means to end the patient’s life or, if the patient is physically unable to do so, ending the patient’s life”. In his evidence Lord Joffe underlined this distinction. “The attending physician may only provide the patient with the means to end the patient’s life, the obligation being or the option being for the patient to decide whether to take these drugs or not as he or she chooses. The only exception to this is where the patient is physically unable to take the medication” (Q 70).
32. With the exception of Clause 8 (Psychiatric Referral), which arguably would sit better earlier in the text, the remainder of the Bill deals with the actions to be taken in the wake of a patient receiving assisted suicide or voluntary euthanasia, with the legal protection of medical personnel involved in the act and with the administration of drugs to patients suffering severe distress. Clause 7 attempts to deal with the situation of persons, and especially physicians, with conscientious objections. Subsection (1) provides a general employment immunity to persons with conscientious objections from being obliged to participate in any way in the process of assisted suicide or euthanasia provided for in the Bill, while subsections (2) and (3) require attending and consulting physicians with conscientious objections to “take appropriate steps to ensure that the patient is referred without delay” to attending or consulting physicians who do not have such objections. In his oral evidence Lord Joffe recognized the difficulty, to which the Joint Committee on Human Rights had drawn attention¹⁹, that an obligation to refer a requesting patient to a colleague could nonetheless be regarded as an infringement of conscience, and he accepted that a new “conscience clause” would be needed in the event that the Bill were to move forward, which would place on the patient the responsibility for finding a physician without conscientious objection.

¹⁸ Clause 6(1)

¹⁹ HL paper 93, HC 603, Paragraphs 3.11 to 3.16

33. Clause 10 of the Bill provides that a physician or member of a medical care team who in good faith complies with a patient's request to die in accordance with the provisions of the Bill shall not be in breach of either the law or any professional oath or affirmation, while Clause 11 makes it an offence to falsify, participate in the falsification of or destroy a declaration.
34. Clauses 13 and 14 provide for the documentation necessary for an audit trail of the operation of the bill. The attending physician must collect the relevant documents, including the patient's declaration and the evidence that all the qualifying conditions have been met, and forward them to a monitoring commission within seven days of the patient's death. The commission, which shall consist of three members—a registered medical practitioner, a legal practitioner and a lay member “with first-hand knowledge or experience in caring for a person with a terminal illness”²⁰, must assess the records and decide whether or not the terms of the law have been fulfilled.
35. Clause 15 provides that “a patient suffering from a terminal illness shall be entitled to request and receive such medication as may be necessary to keep him free as far as possible from pain and distress”. Lord Joffe explained the need for this section, which appears out of character with the rest of the Bill, as follows: “There is clear evidence that many patients do not get sufficient pain relief, for any one of a number of reasons. Research published by CancerBACUP this year demonstrates that a large number of patients are not even consulted about their pain relief. Research from the Nuffield Trust last year found that a considerable number of patients actually suffered unnecessary pain which could have been prevented”. Lord Joffe added: “There is a further factor which is also very relevant to this clause, and that is that it is clear that there are a number of doctors who are concerned about using the double-effect principle in order to ease the pain of their patients because they are frightened that they may be prosecuted” (Q 70).
36. The Bill as drafted does not extend to Northern Ireland. Lord Joffe has, however, announced his intention to exclude Scotland also from its ambit on the grounds that the issues covered by the Bill are devolved to the Scottish Parliament.
37. Lord Joffe described his Bill to us as “a deeply humane piece of legislation which will protect patients as well as their physicians and families” (Q 70). Lord Joffe has pointed out that his Bill “contains many more safeguards than other-end-of life practices which hasten death in the United Kingdom” (Q 70) and that “in all these cases there is no legislation, no safeguards whatever. There are guidelines in relation to withholding treatment and advice given by the General Medical Council or the BMA... but there is no legislation” (Q 98).
38. We now proceed to examine the fundamental ethical principles underlying the Bill (Chapter Three) and a range of practical issues concerned with its implementation in the event that it were to become law (Chapter Four).

²⁰ Clause 14(2)

CHAPTER 3: THE UNDERLYING ETHICAL PRINCIPLES

Introduction

39. In our introductory chapter we observed that the supporters and opponents of the ADTI Bill based their arguments on two first principles—personal autonomy in the one case and the sanctity of human life in the other. Before proceeding to examine these concepts, it is necessary to make the—perhaps obvious, though easily overlooked—point that the difference of principle between the Bill’s supporters and its opponents is not that the former do not believe in the sanctity of human life or that the latter do not support personal autonomy. It is clear to us from the evidence we have received that each side values both these principles. The difference between the two points of view is that in the circumstances envisaged in the Bill one side takes the view that, where there is a conflict between the two principles, personal autonomy should prevail, while the other side gives precedence to the sanctity of human life.
40. In this chapter we summarise, first, the arguments and counter-arguments which have been put to us by our witnesses on both these subjects, and then the conclusions which might be drawn from our analysis of them.

Nature of Personal Autonomy

41. Autonomy was defined for us by Professor John Harris, Bio-ethicist and Philosopher at the University of Manchester, as “the ability to choose and the freedom to choose between competing conceptions of how to live”. “It is only by the exercise of autonomy,” Professor Harris continued, “that our lives become in any real sense our own. The ending of our lives determines life’s final shape and meaning, both for ourselves and in the eyes of others. When we are denied control at the end of our lives, we are denied autonomy” (Q 1).
42. To a large extent, of course, autonomy over the time and mode of one’s own death already exists—as suicide is not an offence in law. The debate in this case is over assisted suicide or, in the case of persons who are not physically able to take their own lives, voluntary euthanasia. It was suggested to us by Professor Jonathan Glover of the Centre of Medical Law and Ethics at King’s College London that there could be a denial of autonomy under the law as it stands at present. It was, he suggested, “discriminatory and objectionable that somebody who is capable of committing suicide is able to do that, but somebody who happens to lack the physical capacity to do that is denied it” (Q 53). The same point was made to us by Baroness Greengross (Q 1913).
43. A more qualified view of autonomy—what was referred to by some as “principled autonomy”—was given to us by the Reverend Professor Robin Gill on behalf of the Church of England—namely, that “the rights of the individual always go hand in hand with the duty of the individual to other people” (Q 1758). The same point was made to us by Dayan (Judge) Chanoch Ehrentreu, on behalf of the Chief Rabbi: “Despite contemporary society’s commitment to individual liberty as an ideal, it recognises that the interest of the individual cannot be separated from the interest of the society at large” (Q 1758). Essentially the same point was made by Ms Hanne

Stinson of the British Humanist Association (BHA)—that “we should all be allowed to make decisions about our own lives unless those decisions are harmful to others” (Q 1810).

44. Yet another view of autonomy was given to us by Ms Alison Davis, National Coordinator of No Less Human, that “the concept of autonomy actually means that you should act in your own best interests, and best interest as traditionally understood means that things such as preserving life, maintaining health, restoring health, minimising suffering... are the sort of things over which we have autonomy” (Q 534).
45. Applying these principles to the field of clinical practice, Professor Alan Johnson, Emeritus Professor of Surgery at the University of Sheffield, observed that “the impression has been given that obeying patients’ wishes is the overriding ethical imperative for doctors. Of course it is important, but it is not paramount. If it were, I would have done many unnecessary operations and some harmful operations in my time as a surgeon” (Q 165). And he cited, as an example of the need to subordinate individual patient autonomy to the interests of the wider patient community, the refusal of doctors to prescribe antibiotics at a patient’s request for relatively trivial conditions because to do so would “produce resistance which might have quite a serious effect on people further down the line” (Q 192). Professor Raymond Tallis of the Royal College of Physicians put it this way: “The big problem is the question of whether autonomy is, as it were, the sovereign bioethical principle... There is no doubt about it; autonomy is the cornerstone of general medical practice... but there are certain issues where there may appear to be conflict between the value of autonomy and other values” (Q 227).
46. The essential argument therefore is that, before rights are given to a minority, it is necessary to consider whether there are likely to be any adverse downstream effects on the majority. The Bill’s supporters would probably agree with Professor Glover that there is no need in this case to balance the rights of a minority against potential harm to larger numbers of people because “under this proposed Bill or legislation broadly of this type, no one who does not want to have access to assisted dying is going to be made to do so” (Q 55). Professor Simon Blackburn, Vice-President of the BHA, felt that “any harm to others would have to be through such an indirect and improbable chain of causation that I think it would be wrong for public policy to take any notice of it” (Q 1812). And Professor Harris put to us an argument to the effect that, without the enactment of the Bill, there is certain harm being done to some people (those who are terminally ill and wish to have assistance to die), whereas there is only potential harm to others (for example, people who might feel pressured to opt for assisted suicide or euthanasia against their better judgement in order to avoid being a burden on their families) if it were to be enacted. “We have to take a balanced view,” he suggested, “but that balanced view should not be at the expense of one group always in order to offer absolute protection to another group” (Q 16).
47. Professor Harris also offered us what he considered to be an analogous situation to a terminally-ill patient who is suffering unbearably and requesting assistance to die. This—the so-called “policeman’s dilemma”—envisaged a motor accident in the United States in which a lorry driver is trapped in the cab of his burning vehicle and in which it is clear that he will be burnt to death before he can be freed. In these circumstances he asks the

policeman who arrives on the scene of the accident to shoot him rather than to let him be burnt alive. The policeman complies with the request out of a sense of humanity. “I have not met a single person,” said Professor Harris, “who could look me in the eye and say that the policeman did a wicked thing and did something that he should not have done. If we concede this case, then we concede the principle of assisting death in extreme distress and where the condition, as the lorry driver’s was, is clearly a terminal one” (Q 2). We return to this analogy later in this chapter.

Autonomy in other End-of-Life Situations

48. Some of our witnesses drew a contrast between on the one hand the legal right of a patient, whether or not terminally ill, to refuse life-prolonging treatment and on the other the inability of a terminally ill patient either to receive the means to commit suicide or to have his or her life ended by someone else. Dr Evan Harris, MP, a doctor, suggested that, while many doctors might not be happy with a patient’s refusal of further treatment, they would accept it on the principle of patient autonomy (Q 5). In the view of Professor Sheila McLean of the University of Glasgow, “what Lord Joffe is doing is putting people who require active assistance on a par with those who have a treatment that they could otherwise refuse” (Q 10). Professor Blackburn took a similar view—that “it is surely discriminatory and unjust to allow deliberate omissions... but to forbid parallel commissions” (Q 1810). It was also suggested to us that there was even more inconsistency between refusing to people active assistance to end their lives and allowing the withdrawal or withholding of treatment which is deemed futile or burdensome without the patient’s consent.
49. These arguments were however contested by others. We were told that, while it might be argued that there was little difference from the patient’s standpoint between on the one hand allowing a refusal of futile or burdensome treatment and on the other refusing assistance with suicide or voluntary euthanasia, from the standpoint of the physician the two situations were quite different—in that he is acceding in the one case to a patient’s request to let his or her illness take its natural course, while in the other he would be required to bring the patient’s life to an end prematurely. According to Professor Timothy Maughan, Professor of Oncology at the University of Cardiff, “this Bill clearly crosses a Rubicon... At the moment we have a clear line, a clear line where we do not kill people actively by the ending of a life”. The Bill, suggested Professor Maughan, “would remove that clear line. To me as a doctor and to my colleagues there is a very clear distinction between what we do now with the removal of treatment and allowing nature to take its course and the active commission of death in this situation” (Q 165). Professor Nigel Leigh, for the Association of British Neurologists (ABN), suggested that a patient’s autonomous demand for assisted suicide or euthanasia could conflict with a doctor’s exercise of his or her own autonomy. While supporting the principle of patient autonomy and indicating that in his personal view a case for allowing “a very small minority” of patients to end their lives could be made, Professor Leigh suggested that patients asking for hastened deaths “have responsibilities to the people who are going to have to do something which is traditionally—and probably always will be—against the medical ethic” (QQ 1127 and 1157).
50. In the experience of Dr Fiona Randall, a consultant in palliative medicine, “patients on the whole can distinguish between refusing a line of treatment

that they do not want and what this Bill is proposing, which is a right to assistance by the doctor directly ending your life. I think to most common people there is a difference between the right not to have treatment forced upon you, which is almost a negative right, and a positive right to have the doctor give you a lethal injection. I think most people could see that those were two different scenarios” (Q 1984).

51. It might perhaps be argued that the case of withholding or withdrawing treatment is more open to question because the patient’s consent to such action is not required if the treatment is deemed futile or burdensome. But here too most of the medical practitioners whom we questioned saw a clear difference between withholding or discontinuing life-prolonging treatment considered to be futile—and often also burdensome to the patient—and taking action specifically to end his or her life. As Professor Sir Graeme Catto of the General Medical Council put it, “We understand the view that there is no moral difference between withholding life-prolonging treatment and taking active steps to end a patient’s life or that there is a continuum which spans both withholding treatment or providing drugs which may have a double effect and taking active steps to end a patient’s life. We understand that view but we do not share it. We believe that active steps to end a life raise questions for society on the value it attaches to human life and the role and responsibilities of those curing or restoring health; indeed, those who are responsible for caring for individuals who are nearing death bear special responsibilities” (Q 285). And it was also pointed out that the withdrawal or withholding of treatment differed from assisted suicide or euthanasia not only in intent but also, in some cases, in its results. Professor Maughan referred to cases “where the ventilator has been turned off and the patient has carried on breathing. The outcome is in doubt when you withdraw intervention. You do not know that it will lead to death. What you are doing is primarily withdrawal of burdensome and futile treatment” (Q 205). Dr Randall argued²¹ that, when futile or burdensome treatment is withdrawn or withheld, the patient’s death results from the failure of essential organ function, which renders the patient incapable of survival without constant life-prolonging treatment. The fundamental cause of a patient’s death in this situation was the patient’s condition, not the withholding or withdrawal of treatment.
52. Finally, it was suggested to us by one of our witnesses that the autonomy of terminally-ill patients should be seen within the context of the struggle to come to terms with the end of life rather than as a simple question of legal entitlement. Dr Rob George, a consultant in palliative care at University College London Medical School, argued on the basis of his own experience that patients requesting assistance to end their lives tended to be “people who wish to be in control... people who are not willing or prepared to engage the issues that may underlie the problems that arise” (Q 356) and that what is needed in such cases is a range of support services to enable the patient to address his or her fears. Dr George described this approach as “respecting the autonomy of the individual as self-government rather than purely self-determination” (Q 367).

²¹ See Volume II: Evidence, HL Paper 86-II, Page 724

Sanctity of Human Life

53. It was clear from the evidence which we took from representatives of religious organisations (see QQ 1758-1809) and from letters we received that many people believe that life is God-given and cannot in consequence be terminated by others, even on request. For them the sanctity of human life is a concept which is closely linked with religious convictions. Some of our witnesses, however, argued that there is also a secular version of this principle. Professor Glover defined this as “an absolute barrier, an absolute ban, not derived from a religious source on the intentional taking of innocent human life”, which he believed to be identical to the religious version (Q 65). “Most human beings,” he continued, “think that the issue of taking someone’s life is a deeply serious issue and one that requires a great deal of justification. I do not think one needs religious authority to take a view like that” (Q 65). The Rev Professor Gill said that, while to Christians life is God-given, “to secular people life is still given, it is given by the people; you did not invent your life. Human life is in that sense special and to be treated with care. Intentional killing is not something any of us should be taking lightly, whether we are religious or not” (Q 1777).
54. Another witness, Lord Walton of Detchant, who chaired the 1993/4 Select Committee on Medical Ethics, referred to “society’s prohibition of intentional killing, a prohibition which is the cornerstone of law and of social relationships. It protects each one of us impartially, embodying the belief that all are equal” (Q 2043). Professor John Finnis of the University of Oxford saw this law as a “bright line”. “Though like other laws,” he said, “it is not invariably respected, it is not in the least artificial or brittle: it rests on a rational principle that a person’s life is the very reality of the person” (Q 1973). Mrs Michele Wates, a researcher and writer, took the view that the Bill would “turn that principle on its head and establish in its place the principle that a person may invite others to kill them” (Q 1973).
55. Professor Blackburn, on the other hand, suggested that “opposition to this Bill is based not so much upon the sanctity of life... but the sanctity of dying: in other words, the essential inviolability of the process of dying in whatever way nature and accident have determined” (Q 1810) and that “the sanctity of life is actually honoured when we give due weight to human suffering, human dignity and human self-determination” (Q 1810).
56. Professor McLean believed that the view of the courts was that “when there is a tension between the State’s underpinning commitment to preserving the sanctity of life and the autonomous decision of a competent person that they no longer wish to have their life protected by the State, the function of autonomy or the value of autonomy is more significant than any adherence to sanctity of life” (Q 16). Dr Evan Harris, MP, added that, “if sanctity of life as a priority were any basis for regulation, then we would seek to prevent competent persons from refusing life-saving medical treatment” (Q 16).
57. The view that, in Lord Joffe’s words, “personal autonomy trumps sanctity of life” (Q 89) in legal thinking derives from a number of court judgments, including that given by Mr Justice Munby in the case of a man (Mr Oliver Leslie Burke) suffering from a congenital degenerative brain condition which would inevitably result in his needing to receive nutrition and hydration by artificial means. Mr Burke sought clarification as to the circumstances in which such treatment might lawfully be withdrawn. Mr Justice Munby ruled that in the final analysis it was for the patient, if competent, to determine

what was in his own best interests; that personal autonomy—the right of self-determination—and dignity were fundamental rights, recognised by the Common Law and protected by Articles 3 and 8 of the European Convention on Human Rights (ECHR); that the personal autonomy protected by Article 8 embraced such matters as how a person manages his or her own death; and that, though there was a strong presumption in favour of taking all steps which prolong life, the obligation was not absolute. “Important as the sanctity of life is, it has to take second place to personal autonomy; and it may have to take second place to human dignity”. In the context of life-prolonging treatment the touchstone of best interests was intolerability²². This judgment is however subject to appeal at the time of writing.

58. It is necessary to consider also judgments given both by the House of Lords (2001) and by the European Court of Human Rights (2002) in response to appeals by Dianne Pretty. Mrs Pretty, who was suffering from motor neurone disease and was paralysed from the neck downwards, though with her intellect and capacity to make decisions unimpaired, appealed against a refusal on the part of the Director of Public Prosecutions (DPP) to give an undertaking that her husband, Brian Pretty, would not be prosecuted under Section 2 of the 1961 Suicide Act if—as Mrs Pretty said she desired—he were to help his wife to commit suicide. The appeal claimed, *inter alia*, that the DPP’s refusal was incompatible with Article 2 of the ECHR and that Section 2 of the Suicide Act was discriminatory—and therefore at variance of Article 14 of the ECHR—because it bore particularly heavily on people whose physical incapacity required the assistance of others if they wished to commit suicide. Both appeals were rejected, and Mrs Pretty died shortly afterwards of natural causes.
59. In giving its reasons for refusal, the House of Lords ruled that Article 2 of the ECHR, which enunciated the principle of the sanctity of human life and provided that no individual should be deprived of life by means of intentional human intervention, did not imply the right of an individual to choose whether to live or die. Having also ruled that Section 2 of the Suicide Act was not discriminatory (because the Act conferred no right to commit suicide), the House of Lords commented that the DPP could not exercise his discretion not to bring a prosecution under that Act in advance of criminal charges being brought. The ECHR judgement followed similar lines, confirming that no “right to die” could be derived from the Convention. It added that “the law which criminalised assisted suicide was designed to safeguard life by protecting the weak and vulnerable, and especially those not in a condition to take informed decisions, against acts intended to end life or to assist in ending life. The blanket nature of the ban on assisted suicide was not disproportionate, as there was flexibility, in that consent was needed from the DPP to bring a prosecution and a maximum sentence was provided allowing lesser penalties to be imposed as appropriate”²³.
60. The question of whether the Bill complied with human rights law was examined by the Joint Committee on Human Rights in its Twelfth Report (Session 2003-04). The Committee took the view that “the Bill is not intrinsically incompatible with ECHR Article 2” and that “its compatibility

²² *R (Burke) v General Medical Council*, Weekly Law Reports 25 February 2005, Page 460, Paragraph 80

²³ *Pretty v United Kingdom*, European Court of Human Rights, Application No 2346/02, 29 April 2002

depends on the extent to which it contains safeguards for the rights of vulnerable patients who do not wish to have their lives terminated with the assistance of a third party”²⁴. Having examined the safeguards in the Bill, the Committee concluded that these “would be adequate to protect the interests and rights of vulnerable patients... While recognising that the Bill relates to exceptionally sensitive matters of life and death and affects people’s rights to life, we do not consider that it gives rise to a significant risk of incompatibility with those Convention rights”²⁵. As mentioned above (see Paragraph 32), the Committee drew attention to Clauses 7(2) and 7(3) of the Bill, which are designed to cater for physicians with conscientious objection to what the Bill proposes and which, in the Committee’s view, posed a significant risk of a violation of Article 9(1) of the ECHR.

Discussion

61. What conclusions can we draw from all this argument and counter-argument on the ethical principles underlying the debate on the ADTI Bill? This section attempts to identify those areas where, as a committee, we are agreed and those where there is not a consensus among us.

Autonomy

62. We are agreed that patient autonomy cannot be absolute and that there must be some limits set, in the interests of the wider community, to what a patient can require his or her doctor to do. There is not consensus, however, on where those limits should be. Some of us take the view that, as the Bill is offering assisted suicide or voluntary euthanasia only to a limited category of patients who ask for it and as the Bill incorporates safeguards designed to ensure that its provisions are not abused, there is no conflict with the interests of the wider community to be considered and that the Bill, if enacted, would therefore represent a logical and desirable extension of personal autonomy. Others among us take the view that personal autonomy, as self-governance, cannot extend to requiring others to perform acts which assist a patient to take his or her own life or deliberately end that life. They also regard the thinking underlying the Bill as unrealistic and they argue that its enactment will lead to a “slippery slope”, whereby assisted suicide and voluntary euthanasia will become more widely available than is intended in the Bill either through incremental extension of the law or through the exploitation of loopholes or, for example, by terminally ill people resorting to them to remove a perceived burden on others.
63. The Bill’s supporters respond to this by pointing to allegations that patients are in practice being given assistance with suicide or receiving voluntary euthanasia covertly and that enactment of the Bill would increase rather than diminish the safety of all terminally-ill people, and that the evidence available from countries where such legislation has been enacted shows little or no evidence of “slippery slopes”. The Bill’s opponents, for their part, point to the absence of hard evidence for the allegations of covert euthanasia and cite evidence from abroad—and especially from The Netherlands—that the “slippery slope” is a reality. What this tells us that we cannot address the issue of personal autonomy in isolation and that we must proceed to look at

²⁴ HL Paper 93, Paragraph 3.6

²⁵ HL Paper 93, Paragraph 3.10

some of the “real world” issues which have been raised and to try to assess the balance between greater personal choice for some people and increased potential harm for others, and also at the experience of other countries where provisions are in force for assisted suicide or voluntary euthanasia. This we do in Chapters Four and Five.

64. We recognise that, from the patient’s point of view, refusing life-prolonging treatment may appear little different from seeking assisted suicide or euthanasia. But we recognise also that there is a clear difference between the two situations from the point of view of the physician, mainly because the intention in the former case is not to bring about the death of the patient, whereas that is indisputably the intent in the case of assisted suicide and voluntary euthanasia, which in the words of Dr Michael Wilks, speaking on behalf of the British Medical Association, “move medicine and medical care into a different field” and create “a different type of relationship between the doctor and the patient” (Q 282). This does not mean, of course, that the medical perspective should automatically prevail. As we remarked in Chapter One, there is consensus among us that, in the last analysis, the acceptability or otherwise of the Bill is a matter for society as a whole. Having said that, we recognise also the crucial role which doctors would have to play in the implementation of the Bill, were it to become law, and that the views of the medical and nursing professions must be considered very seriously.
65. The parallel which has been drawn with the withdrawal or withholding of treatment is less straightforward. Where this is done at the patient’s request, it falls to be considered in the same category as the refusal of life-prolonging treatment. Where it is done without the patient’s consent, it is easy to understand why some people might take the view that it is more of an infringement of the patient’s rights than assisted suicide or voluntary euthanasia. We can, however, see the force of the counter-argument that the intention is not to end the patient’s life but to discontinue treatment which is futile and burdensome; that doctors are under no obligation to strive officiously to keep their patients alive at all costs; and that it is not unknown for patients who have had life-prolonging treatment withheld or withdrawn to continue to live.
66. We turn now to the observations which Professor Harris made to us (see Paragraphs 46 and 47 above) that there is a need to balance actual harm to patients who wish for and are denied assisted suicide or voluntary euthanasia against potential harm to other patients who might be exposed to exploitation if the Bill were to be enacted; and that, if society can accept that there are circumstances where what is commonly known as “mercy-killing” is justifiable, then the principle underlying Lord Joffe’s Bill cannot be denied—the so-called “policeman’s dilemma”.
67. There is clearly a need to balance the interests of terminally-ill people who wish for assistance to end their lives against those of patients who do not. But this cannot be seen as a simple matter of weighing a certainty against a doubt and coming down in favour of the former. In any cost-benefit analysis—because that is just what this is—the balance of advantage needs to take into account the different weightings on each side of the scales. In this case it is necessary to know, for example, how many people are being deprived of benefit on one side of the equation and how many others might be endangered on the other side. We need also to take a view of the size of the benefits to the one group as against the magnitude of the damage to the

other. So, while the principle of what Professor Harris has said is fair, it is necessary to look further (in Chapter Four) at how the balance would look in practice if the law were to be changed.

68. As for the hypothetical “policeman’s dilemma”, no one would pretend that the sort of situation which this postulates represents other than a very rare scenario, for which no legislature would consider providing in law. Commenting on this hypothesis, the Rev Professor Gill drew a distinction between compassion and legalisation. “It is a hugely compassionate case,” he said, “and I would do exactly as the policeman did, and I hope you would too. But I would not expect the law to be changed to allow that; indeed, it would produce absolute chaos in society if we really did allow the police the discretion of shooting people in that context” (Q 1761). We note here what the law says now about so-called mercy-killing—that, if anyone should take upon him or herself the responsibility for ending someone else’s life in order to prevent suffering, he or she must let the courts examine all the facts of the case and reach a judgement on guilt or innocence and on whether, and if so to what extent, the law should impose punishment.

Sanctity of Human Life

69. We have less to say on this subject because it has been discussed to some extent implicitly in our examination of personal autonomy, of which in this specific context it may be regarded as the obverse. Some of us feel strongly that legalisation of assisted suicide or voluntary euthanasia would mark a fundamental departure in society in that it would make it lawful for one human being to comply with another’s request to end or assist in ending his or her life. There are, however, certain other points which need to be made.
70. The first of these stems from an observation which was made to us by Dr Evan Harris, MP, and which is recorded in Paragraph 56 above—that, if the sanctity of human life provided a basis for opposing assisted suicide or voluntary euthanasia, there would be moral problems over allowing terminally-ill people to refuse life-prolonging treatment. While Dr Harris has raised an important issue here, our evidence suggests that most of those who accord to the sanctity of human life priority over personal autonomy would not see a moral inconsistency between opposing assisted suicide or voluntary euthanasia and accepting the refusal of life-prolonging treatment. This is because they would not see a refusal of life-sustaining treatment as tantamount to suicide—and we note the statement of the Attorney-General that this view reflects the position in law (Q 2074).
71. We have considered also the principle of whether, if the Bill were to be enacted, its licence for assisted suicide or voluntary euthanasia would be consistent with society’s attitude to suicide in general. More specifically, we have asked ourselves whether there is not an inconsistency between discouraging suicide for most people—to the point of taking strenuous measures to dissuade people from it and attempting to resuscitate those who do—and providing for a small group to have assistance in the act. When we put this question to Professor Glover, he replied: “Because the act of suicide is such a serious one and so irrevocable if successful, if somebody comes into hospital unconscious having attempted suicide, there is a strong moral case for reviving them, unless you have masses of documentation showing that this was a very serious thing which has been discussed and planned” (Q 66). But Professor Glover was less sure about the morality of reviving someone

who had “gone through all the types of procedure which this Bill envisages” and he suggested that, “in prison my worry is that it might be someone, say, serving a life sentence, might have a very serious wish to die, but one of the ways in which prison may be an abrogation of that person’s rights is that they may not be allowed to do so” (Q 66).

72. Mrs Michele Wates was disturbed by the line which, in her view, the Bill drew “between those who ‘qualify’ to be assisted in killing themselves and those whom society would seek to prevent from committing suicide” (Q 1973). Commenting on a hypothetical comparison between a terminally ill patient with unbearable suffering and a person about to kill himself by jumping off a bridge, Professor Tallis—giving evidence on this occasion in a personal capacity rather than on behalf of the Royal College of Physicians—took the view that “in different situations there are different principles that come to the fore. It seems to me that in this particular principle of the person jumping off the bridge it [i.e. intervention] is totally appropriate and the principle of beneficence would rise above the principle of autonomy until you sort through what is going on. In the situation of a person who is terminally ill and has unbearable suffering, then I think autonomy starts to push into the front and some principled concept of beneficence which overrides what they want starts falling behind” (Q 1960). Professor Finnis, on the other hand, wondered why, if autonomy were the principle underlying the Bill, its provisions were limited to people with terminal illness or unbearable suffering (Q 1973). In other words, while terminally ill people requesting assistance with suicide might be suffering unbearably, others—such as people suffering from chronic debilitating conditions or even (for example, prisoners serving life sentences) from no serious medical condition at all—might be in the same position. Yet, as was made clear to us by the Attorney-General (QQ 2101 and 2109), the law requires—and would continue to require even if assisted suicide or voluntary euthanasia were to be legalised—that action be taken to frustrate attempted suicides by, for example, prisoners.
73. Having examined in this way the principles underlying Lord Joffe’s Bill and recorded where we feel able to agree and where as a committee we disagree on them, we shall proceed now to consider some of the key issues of practice.

CHAPTER 4: PRACTICAL ISSUES

Introduction

74. In this chapter we examine a number of key issues concerned with the reality, as distinct from the principles, of the subject with which the ADTI Bill is concerned. We have focused on a number of practical issues which have been raised with us in the course of our inquiry and which are concerned to a large extent with the potential of a change in the law for causing harm to others, both patients who might be at risk and those who would be called upon to assist in the ending of lives. We set out the issues here in the form of questions, and then we examine each of them in turn.
75. The issues which we shall address may be summarised in the following questions:
- **Covert Euthanasia** What evidence is there that it is already taking place? And would the interests of terminally-ill people be better protected if the situation were to be recognised and regulated by legislating for assisted dying and euthanasia with the safeguards proposed in the Bill
 - **Palliative Care** Given recent and prospective advances in this area, can good quality palliative care remove most kinds of terminal suffering? And to what extent do these advances undermine the need for legislation along the lines proposed in the Bill?
 - **Slippery Slope** Would enactment of the Bill involve a “slippery slope”, whereby the safeguards which the Bill contains would be eroded either by subsequent amendments to the law or by abuse of the provisions in the Bill or by undesirable changes in medical ethics?
 - **Doctor-Patient Relationships** Would these be damaged or improved by the Bill?
 - **Conscientious Objection** Is the position of doctors and other health care staff with conscientious objections to assisted suicide or voluntary euthanasia adequately protected in the Bill? And would the numbers of such staff opting out of implementing the Bill on grounds of conscience be likely to make it unworkable?
 - **Prognosis** How accurately is a doctor able to predict that a terminally-ill patient will die (in the words of the Bill) “within a few months at most”? And how would this timeframe in the Bill affect people with degenerative diseases, whose prognosis is more problematic than that of others with malignant conditions?
 - **Competence** Can an attending or consulting physician be expected to be able to identify in patients requesting assisted suicide or voluntary euthanasia the presence of psychological disorders which could impair their competence to make such requests?
 - **Unbearable Suffering** Can doctors reasonably be expected to be able to assess whether a patient’s suffering is unbearable?

- **Demand** How widespread is the serious demand for assisted suicide or euthanasia? And to what extent is this influenced by the scope of legislation in this area?
- **Vulnerable Groups** What evidence is there to suggest that the Bill could expose particular groups of people, such as the disabled or the elderly, to the danger of assisted suicide or euthanasia?

Covert Euthanasia

76. The allegation that covert euthanasia is being practised in the United Kingdom was made by the Voluntary Euthanasia Society (VES) in its written evidence to us²⁶. In oral evidence Deborah Annetts, the Society's Chief Executive, told us that "we have evidence that doctors and relatives are breaking the law... The law is clearly not working" (Q 1).
77. We have looked at the evidence to which our attention was directed. In most cases it consists of the results of surveys carried out on the subject of assisted suicide and euthanasia, including questions on whether the respondents had ever broken the law or knew anyone else who had done so. More specifically:
- *Ward, Bf and Tate, PA "Attitudes among NHS Doctors to Requests for Euthanasia" BMJ May 1994*

In a survey of GPs and hospital consultants, of 312 respondents (who had been assured of their anonymity) 38 (12%) claimed to have complied with a patient's request to hasten death.

- *Sunday Times 15 November 1998*

A study of 300 GPs was said to have revealed that one in seven had admitted to helping patients to die at their request and that "hundreds, probably thousands, of patients die each year with the help of doctors at home, in hospices and in hospital".

The article also gives the names of two doctors who, between them, claim to have assisted up to 12 people to die at their request.

- *McLean, S "Survey of Medical Practitioners' Attitudes towards Physician Assisted Suicide (June 1996)*

This was a postal survey with 1,000 respondents. 12% of respondents "personally knew another health professional who had assisted a patient to kill themselves" and 4% had "provided the means (such as drugs or information about lethal acts) to assist a patient to kill themselves".

- *Medix Survey 8 August 2004, Sponsored by the Voluntary Euthanasia Society*

Of 1,000 respondents, 513 (51%) answered "Yes" to the question: "Do you believe there are circumstances where some health professionals in the United Kingdom currently give pain relief to terminally ill patients with the intention of shortening their life?" 454 respondents (45%) answered "Yes" to the question: "Do you believe there are circumstances where some health professionals in the United Kingdom currently assist in the suicide or voluntary euthanasia of their terminally ill patients?"

²⁶ See Volume II: Evidence, HL Paper 86-II, Pages 2-3

78. Ms Hanne Stinson, of the British Humanist Association, also felt that covert euthanasia was taking place, though she was more cautious in her assessment of its incidence. “Because it is unlawful,” she told us, “we have no idea how often it is done” (Q 1810).
79. By contrast, Dr Michael Wilks, of the British Medical Association (BMA), said that “we have no evidence whatever” (Q 287) of covert euthanasia. Professor Sir Graeme Catto, of the General Medical Council (GMC), took a similar view. Asked for his views on the allegations which had been made, he replied that, “we have no evidence that this is the case, and we have had a discussion this morning about the anecdotal nature of some of these reports. No doubt there is some truth behind them, but we have no objective evidence of which I am aware that this exists” (Q 325). Professor Catto also told us, when asked whether doctors were being disciplined as the result of complaints in this field from fellow professionals, relatives or other members of the public, that “we have no evidence to that effect. The number of cases coming forward in that area, I think, has remained very small. We have no evidence to support that suggestion” (Q 296). Dr Wilks suggested that there was confusion on the part of some of those who alleged covert euthanasia between, on the one hand, the legal and (from the point of view of medical ethics) acceptable acts of withdrawing or withholding ineffective treatment and giving pain relief and, on the other, the administering of euthanasia. Not ruling out the possibility that there were occasional cases of malpractice, he added that, “the number of times that doctors do things intending the death of the patient is actually, I think, very small; and I would think, given the highly-controlled regulatory structure around hospitals—and particularly as we remember that in this country most people do die in hospitals—highly unlikely” (Q 287). We comment further on this subject in Chapter Seven.

Palliative Care

80. This is a substantial subject. Here we can do no more than summarise the issues, which for convenience we sub-divide into three main questions:
- What exactly is palliative care?
 - How good is it, and how readily available to the terminally-ill, in the United Kingdom?
 - What can it do to reduce or eliminate “unbearable suffering”?

Definition

81. It is necessary to be clear about the nature of palliative care. It is often associated with palliative medicine, which is just one aspect of palliative care, and with pain relief in particular—whereas in practice palliative care extends more widely than either pain relief or the administration of medicine. It may be helpful therefore to begin with the World Health Organisation’s definition of palliative care, which was supplied to us by the Association for Palliative Medicine of Great Britain and Ireland (APM)²⁷:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification

²⁷ See Volume II: Evidence, HL Paper 86-II, Page 140

and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”.

82. Dr Vivienne Nathanson of the BMA told us that, “palliative care does a great deal more than pain control or symptom control: it also gives a great deal of psychological support, helping people to come to terms with what has quite clearly been a devastating diagnosis or with devastating news at the end of a process of treatment” (Q 306). Dr Nathanson also said that “many patients who raise questions about the end of life and euthanasia or suicide, sometimes in very heavily coded ways and sometimes more explicitly, are very often asking quite simply: ‘What services will be available to me if I develop symptoms that I cannot accept, that are intolerable to me?’ It is not always pain. It is very important to realise that symptoms that people are most worried about are very varied. They want reassurance. I remember well one patient saying to me very explicitly: “What I want to know is that I will not be abandoned: there will not be a stage at which people say ‘There is nothing more we can do for you’... That is a very important reassurance to give, to say that we do not abandon people, that we will always look for what else we can do; and sometimes those solutions are high technology, but very often they are low technology and are about reassurance” (Q 323).
83. We were told that the essence of palliative care was team-working. “The practice of palliative care,” said Dr Teresa Tate of the National Council for Hospice and Specialist Palliative Care Services (NCHSPCS), “is of most benefit to a patient and his family when it takes place in a trusting evolving relationship during the course of advanced illness, and not just in the terminal phase, with the multi-professional team providing care which allows complex psychological and spiritual issues to be aired and addressed over time” (Q 354). By contrast, we were told, “referrals in the last two to four weeks of life are a nightmare to manage because everything is moving simultaneously and often things are out of control for them, so the ability to help them make sense and get things in order becomes that much more pressurised and difficult for them” (Q 411). Part of the task is to identify and treat depression (Q 409), to address the range of concerns which patients have about the end of life (Q 323) and to “explore and engage with the patient’s suffering” (Q 354). Good palliative care includes also assessing, and constantly re-assessing during the course of a terminal illness, the most appropriate pain-relieving drugs and dosages to prescribe for each patient. In cases where death is imminent, this can involve terminal or palliative sedation, which means using “proportionate doses of a sedative for symptom control and... the alleviation of distress”²⁸.

Quality and Availability

84. There was consensus among our witnesses as regards the quality and availability of specialist palliative care in this country. The essential message which our witnesses gave to us is that palliative care in the United Kingdom is of a very high quality but inadequately resourced and unevenly spread. Britain was described to us as “a world leader” (Q 354) in this field, and we were told that the development of palliative care as a speciality was “a great British success story, because much of the palliative care movement has been

²⁸ See Volume II: Evidence, HL Paper 86-II, Page 140

British-led” (Q 306)²⁹. “When I first started in practice,” Professor Johnson told us, “the whole idea of palliative care in hospices was just starting, and I can think of some examples where we were very bad at managing symptoms at that time. The improvement and the effect on general care in hospitals has been dramatic: it is not just in hospices and palliative care institutes, it is in general care and pain relief” (Q 182).

85. On the other hand, the availability of good palliative care seems less encouraging. There are, we were told, 237 palliative care consultants in England (the whole-time equivalent of 169), with 100 posts unfilled; and 3195 palliative care beds in the United Kingdom, of which 2522 are in the voluntary sector.³⁰ The Royal College of Nursing (RCN) wrote that “a shortage of community palliative care teams means that patients who want to die naturally at home are not always given that option. In particular, while adults with a cancer diagnosis for the most part now receive good palliative care services, many patients with other terminal diseases—such as degenerative motor neurone disease or chronic obstructive pulmonary disease—are not able to access appropriate services”³¹. The Royal College of Physicians observed that “clinicians working with dying patients are acutely aware of the shortfall of such services in the United Kingdom at present, especially for patients dying from non-cancer deaths outside of hospital” (Q 223). Dr Carole Dacombe, Medical Director of St Peter’s Hospice Bristol and a palliative care practitioner, referred to a “deficit of care” in this field. “It is,” she felt, “an indictment of our society that the vast majority of specialist palliative care services in this country are still delivered by and funded by the charitable sector” (Q 1913). Dr Nathanson added that, “by the nature of palliative care, it is not something that people should be waiting for: it needs to have sufficient resources to be available promptly to people in need at the time that they are in need but the sad fact is that we have not had a sufficient investment to guarantee that every patient who could benefit from this gets that treatment” (Q 306). We were also told of evidence that the patchy provision of palliative care might work to the disadvantage of certain ethnic minorities (Q 28). There is, it was suggested, something of a “postcode lottery” here.
86. Professor Kathleen Foley, a neurologist at the Memorial Sloane-Kettering Cancer Center in New York, told us that “the WHO, in developing its initiatives in palliative care, has asked governments not to consider such legislation for physician-assisted suicide and euthanasia until the needs of their citizens had been met with pain and palliative care services. Clearly Britain is a leader in advocacy for hospice and palliative care, yet the full penetration of services in your own country is not available, as in mine, and especially is not available for those of our ageing population with non-cancer diagnoses” (Q 2116).
87. Professor Mike Richards, National Cancer Director at the Department of Health (DoH), acknowledged to us the limitations of current provision. “Geographical provision,” he said, “is uneven and does not always match need. Much of specialist palliative care at the moment deals with cancer

²⁹ In the United Kingdom higher specialist training to consultant level in palliative medicine takes four years, whereas in other countries, including the USA and The Netherlands, there is no such specialist training and the speciality of palliative medicine is not recognised.

³⁰ See Volume II: Evidence, HL Paper 86-II, Page 135

³¹ See Volume II: Evidence, HL Paper 86-II, Page 97

patients, and I think there is an inequity there in terms of patients, for example, with heart failure or emphysema, who often have similar levels of symptoms but do not necessarily go to specialist palliative care services” (Q 423). The DoH programme, Professor Richards continued, “had three main strands—”firstly, enhancing specialist palliative care services; secondly, enhancing old age specialist services; and, thirdly, skilling-up what we refer to as generalists, that is a whole range of different people: GPs, district nurses, hospital staff who are involved in end-of-life care, and indeed staff in care homes as well” (Q 423). Nonetheless, there was a long way to go. The number of GP practices which had undergone postgraduate training to the Gold Standard set by the DoH was as yet only some 1,600 out of a total of between 10,000 and 11,000 (Q 429), while over the last three years palliative care training had reached only some 10,000 out of around 40,000 district nurses (Q 434). Up-skilling of the 600,000 care assistants in residential homes presented even greater challenges (Q 435). Professor Richards confirmed the national shortage of palliative care specialists. “There are very roughly 250 of them in the country. If you compare that to the number of people dying, which is over 500,000, you can see that for every specialist in palliative medicine there are over 2,000 people dying” (Q 436). However, a start had been made: the DoH had committed an additional—and ring-fenced—£50M and “extra consultants, extra nurse specialists and extra hospice beds have been provided, so it is not just money; it is services that are happening out of this” (Q 442).

Effectiveness

88. There was a general consensus among our witnesses as regards the limitations of palliative care in relieving patient suffering. The VES took the view that “no amount of palliative care can address some patients’ concerns regarding their loss of autonomy, loss of control of bodily functions and loss of dignity. An ability to meet these needs arises not because of a failure of palliative care but because these are person-centred issues. These issues most frequently lie at the heart of a request for help to die”³². Dr David Cole, a consultant oncologist at the Oxford Radcliffe Trust, took the same view. “There is a group of patients,” he told us, “who continue to have intractable distress despite the input from expert palliative medicine, expert general practitioners, etc. That small group of patients who continue to suffer intractable distress may express a wish to choose the time at which they want to die” (Q 1907). The BMA echoed this view, observing that “there are patients for whom even the best palliative care is not dealing with their pain”, adding that “in spite of excellent palliative care, the position is not necessarily one which those patients regard as beneficial to them... the loss of autonomy” (Q 304).
89. While it seems clear from the evidence which we have received that good palliative care, tailored expertly to the individual needs of the patient, can largely relieve the symptoms of physical pain, it is necessary to consider also what it can do for patients suffering from degenerative diseases whose suffering is less of pain as of losing control of their bodily functions, including such basic activities as swallowing. We therefore sought advice from Dr Richard Hillier, a palliative care consultant and one of our specialist

³² See Volume II: Evidence, HL Paper 86-II, Page 3

advisers, on the incidence, symptoms and treatment of motor neurone disease (MND). His advice, based on research carried out by him, is reproduced as Appendix 5. Briefly, MND afflicts up to 2 people per 100,000 in the United Kingdom and there are around 1,000 deaths from it (out of some 500,000 for the United Kingdom as a whole) every year. Most of the symptoms can be relieved or reduced, the more so if patients are treated in a specialist MND Centre with access to experienced physicians, nurses, physiotherapists and palliative care experts. Unfortunately, such centres are few in number, though increasing, and as a result patients who are not involved can suffer considerably. MND sufferers are often fearful following diagnosis, particularly as the result of stories in the media that they will choke to death. Dr Hillier's research concludes that such an outcome is a rarity and that most MND sufferers die of respiratory failure in their sleep. The picture here therefore appears to mirror that for the effectiveness of palliative care overall—that in qualitative terms it can mitigate to a large extent the medical suffering associated with terminal illness but that it is, at least at present, spread too thinly within the United Kingdom.

90. We have noted the advances in specialist palliative care which have been made in recent years in this country and the high quality of such care nationally. We have noted also that such services are not uniformly available throughout the country, though we are pleased to see that the Government is devoting increased resources to this area of health care. We are unanimously of the view that high priority should be given to the development and availability of palliative care services across the country and we hope that the efforts which are being made in this direction will be intensified.

The Slippery Slope

91. Opponents of Lord Joffe's Bill frequently draw attention to the so-called slippery slope, by which they mean that it will be difficult, if not impossible, to prevent the extension of assisted suicide or voluntary euthanasia if once the principle is conceded. The concerns which have been raised with us under this heading may be sub-divided into five categories:

- incremental extensions to the law;
- elastic interpretation of the law's provisions;
- hidden pressures;
- abuse of the law;
- the paradigm shift.

We address these five concerns in turn.

Incremental Extensions

92. Lord Joffe foresaw the possibility of subsequent amendments to his Bill, should it become law, to widen its scope. "We are starting off," he said, "this is a first stage... I believe that this Bill initially should be limited, although I would prefer it to be of much wider application, but it is a new field and I think we should be cautious" (Q 89). Expanding on this, Lord Joffe told us that, "when we considered the opposition to the previous bill, we felt that there was such strength of feeling in the debate about extending it to younger people who had a long lifetime ahead of them that we thought it wise... to

limit it to terminally ill patients who were already suffering terribly and had a very short time to live. But I can assure you that I would prefer that the law did apply to patients who were younger and who were not terminally ill but who were suffering unbearably, and if there is a move to insert that into the Bill I would certainly support it” (Q 124).

93. Dr Fiona Randall argued that, “if we are saying that the entitlement to assisted suicide and euthanasia (and that is what this Bill is about—it is about giving these people an entitlement if they meet certain criteria) is thought to be of benefit for those who are terminally ill, it must be extended to others who feel they are suffering unbearably but are not in the last few months of their life”. Otherwise, she suggested, the law would be regarded as inequitable (Q 1973). Professor Henk Jochemsen, a medical ethicist from whom we took evidence in The Netherlands, drew attention to ongoing debate in that country about extending the existing law on euthanasia to cover new categories of persons, including new-born babies and others without medical conditions who are “tired of life” (Q 1510). We can do no more here than note that the Bill, if enacted, is seen by some of its supporters as (in Lord Joffe’s own words): “a first stage and possibly the final stage, but there could be subsequent stages” (Q 122) and by its opponents as the first step onto a slippery slope.

Elastic Interpretation

94. Many of the people who have written to us have drawn parallels between the Bill and the Abortion Act of 1967. They have pointed to the similarity between the arguments advanced to support the latter (that illegal abortion was already happening and that it would be better to regulate it via legislation) and those used to advance the present Bill, and to the disparity between the intention of the Act’s sponsors—that abortion would be an exceptional procedure—with the reality, in which at the last count there were over 180,000 abortions carried out annually in England and Wales. Their concern is that the legalisation of euthanasia, even with the strictest of safeguards, might have similar results. In his evidence to us, Lord Walton cited experience of the Abortion Law. “I do not believe,” he said, “that the Abortion Act has been significantly amended in relation to its provisions but those provisions have been widely ignored, leading virtually to abortion on demand” (Q 2070).
95. There are, of course, dissimilarities between the Bill and the Abortion Act. The latter, for example, allows abortion in cases where there is considered to be risk to the physical or mental health of the mother or her other children as well as to her own life. There is also a difference from the ADTI Bill in the nature of what is on offer. Whereas it was, perhaps, to be expected that there would be growing pressures to apply the Abortion Act with growing elasticity in an age of increasing secularity, most people have a natural desire to remain alive and in consequence there is unlikely to be the same degree of pressure to exploit loopholes in a law permitting assisted suicide and voluntary euthanasia. Nonetheless, there is a concern that what has been seen as elasticity in interpreting some of the Act’s provisions (for example, concerning the mental health of the mother) might be replicated in implementing some of the Bill’s provisions, including those of “unbearable suffering”, “terminal illness” and “competence”. This concern, Lord Walton told us, is one of the reasons why the 1993/4 Select Committee on Medical

Ethics rejected any change in the law. “We did not think it was possible,” he said, “to set secure limits on voluntary euthanasia... It would be next to impossible to ensure that all acts of euthanasia were truly voluntary and that any liberalisation of the law was not abused. We were concerned over the possible erosion of any such legislation, whether by design or inadvertence or by the human tendency to test the limits of any regulation” (Q 2043). As regards the present Bill, Lord Walton thought that “it would in the first instance set down very strict criteria, but I think those criteria might well be progressively eroded with the passage of time, leading to widespread practice of voluntary euthanasia” (Q 2043). Later in response to a question Lord Walton said: “I have read it [the Bill] carefully several times and, if it were to become law, I cannot readily see any additional safeguards which I would wish to see introduced” (Q 2065).

96. The Bill’s supporters argue that there is no evidence of legislative drift in countries where legalised assisted suicide or voluntary euthanasia have been introduced. They point out that in Holland, for example, there has been no dramatic rise in the number of recorded cases of euthanasia since Dutch practice in this field was codified into law in 2002; and that the numbers of people receiving assistance with suicide in Oregon under the terms of the 1997 Death with Dignity Act has remained relatively stable and low—some 0.14% of all deaths in Oregon in 2003. More detailed evidence of the practice of assisted suicide and euthanasia in these places is provided in Chapter Five.

Hidden Pressures

97. The essential concern under this heading is that some terminally ill people might feel under pressure, if the option of assisted suicide or voluntary euthanasia were to be available in law, to avail themselves of it in the interests of others (in particular, family members) rather than because they themselves positively wished to die in this way. Maura Buchanan of the RCN suggested that some terminally ill patients “might feel that they had to use the Bill when the cost of nursing home care started to eat away the family’s inheritance. It would be easy to succumb to pressure and feel that you had to give up or feel that you were a burden, when the family in today’s world do not sit at home looking after mother or elderly relatives, because everybody has to work now to keep the mortgage going” (Q 263). Baroness Greengross took the view that “the whole question of being a burden to society as a whole is something that is widespread amongst older people, especially in Northern Europe and North America. It is part of our culture, where a lot of old people say they do not want to be a burden on their families, however loving, and we must accept that is part of our culture” (Q 1956). Dr Jim Gilbert, a medical director of palliative care in Devon, raised a related concern—that some patients, while not opting for ending their lives, would feel themselves to be presented, if the law were to be changed, with an ongoing choice to be made (Q 1973).
98. The VES on the other hand argued³³ that, where such “burden” feelings are present in people who wish to die, this is related to their frustration at being dependent on others during the dying process and is therefore linked to losing autonomy. The VES also suggested, drawing on research into assisted

³³ See Volume II: Evidence, HL Paper 86-II, Page 5 and Q18

suicide in Oregon, that “sometimes a patient will hold off going through the final act of having help to die for a few days as a result of their relatives putting pressure on them not to do so” (Q 11). And Baroness Greengross added to her view of the cultural problem (referred to above) that “the burden question is a societal problem... that is about a re-allocation of resources, training care staff better and changing our culture, and not about this Bill” (Q 1956). It was also suggested that people who have a positive wish for assisted suicide or voluntary euthanasia and are denied its fulfilment are the victims of the law as it stands as much as others who might be pressured into such action if the law were to be changed. “Concern for the vulnerable,” said Professor Harris, “does not... tell us that we should forbid medically-assisted dying; it tells us that we should permit it, with the safeguards such as those in Lord Joffe’s Bill” (Q 1).

99. Nonetheless, this is the concern which has been raised with us most frequently in the context of the slippery slope both by witnesses giving oral evidence and in very large numbers of letters and emails from members of the public. As we will see later in this chapter, it is a concern which is felt particularly strongly in relation to potentially vulnerable groups of people, such as the disabled and the elderly.

Abuse of the Law

100. The concern here is that the provisions of the Bill, if enacted, might be applied to persons for whom it was not intended, not because of elasticity in the interpretation of what the Bill allows, but rather through deliberate flouting of the law. While this may seem a less likely outcome, the concern which is felt under this score appears to be that, if (as has been alleged) covert euthanasia is taking place when there is an absolute legal prohibition of it, the opening of the door via limited legal provision will encourage the *de facto* barriers to be pushed further out—rather than (as others argue) the reverse. Those who have this concern usually quote empirical data from The Netherlands which indicate that around 1,000 cases of euthanasia occur annually in that country without an explicit request³⁴. This phenomenon existed before legalisation of voluntary euthanasia in The Netherlands and first came to light in the early 1990s, and the numbers have remained more or less constant. We deal with this issue more fully in our chapter on overseas experience (Chapter Five).
101. Commenting on this, Deborah Annetts of the VES said: “Yes, this is a concern and the Dutch absolutely recognize it and they have been working very hard to try and put in better provisions—if you like, better medical practices—in order to deal with that issue. What is noticeable, though, looking at the 900 deaths which occurred without explicit request, is that most of those patients will have made a request to the doctor; they may not have gone through the formal process but they will have gone through an informal discussion. The latest figures from The Netherlands show that in virtually all those cases there will have been a discussion, if not with the patient themselves but also with the relative or a colleague” (Q 13). The VES added that no increase in this type of case had been reported over the last 10

³⁴ See Volume II: Evidence, HL Paper 86-II, Page 393

years and that in most cases the amount of time by which, according to the physician, life had been shortened was a few hours or days³⁵.

The Paradigm Shift

102. Though this is a term coined by one of our witnesses, it refers to an issue highlighted also by others. The essence of the concern here is that, if assisted suicide and voluntary euthanasia should be legalised and if implementation of the law were to be carried out within the health care system, these procedures will of necessity become a therapeutic option; that over time there will be drift from regarding the death of a patient as an unavoidable necessity to regarding it as a morally acceptable form of therapy; and that pressure will grow as a result for euthanasia to be applied more widely—for example, to incompetent people or to minors—as a morally acceptable form of medical therapy which is considered to be in the patient’s best interests. Professor Tallis told us—adding however that it was his personal view rather than that of the Royal College of Physicians—that “to me it does seem to be a therapeutic option, as are many other forms of treatment that may hasten people’s deaths... For that reason I do feel it should be regarded as part of the therapeutic alliance between the patient and the doctor. I do see, without trivializing the phrase, that it is part of a whole package of care” (Q 257). The Association for Palliative Medicine said that “the Bill postulates the ethical concept that death is a “moral good”. There is the danger that, if death and “medicalised killing” become regarded as in the best interests of competent patients, there will be a moral obligation to extend this to incompetent patients”.³⁶
103. Concern has been expressed over the effect of such a paradigm shift on medical practitioners as well as on patients. “If,” Dr George observed, “under some circumstances assisted suicide or euthanasia is now considered to be an entitlement of the patient—bringing it into statute makes it an entitlement—then that becomes a therapeutic option and, therefore, it becomes a potential duty for us to perform” (Q 420). There is, of course, provision within the Bill for those with conscientious objections to remove themselves from its implementation, and an amendment by Lord Joffe provides that there would be no duty on any doctor to raise the issue with a patient. But the perceived problem here is more about the impact of a law along the lines of the Bill on medical ethics as a whole rather than on individual practitioners.

Doctor-Patient Relationships

104. The concern which has been expressed on this score needs to be looked at from two standpoints—that of the patient and that of the doctor. On the one side, it has been suggested that the legalisation of medical assistance for suicide and voluntary euthanasia could introduce a sense of distrust of doctors on the part of patients. On the other side, it is clear that many doctors are concerned that the introduction of assisted suicide and voluntary euthanasia as medical procedures could not only undermine their patients’ trust in them but also run counter to the ethics of their profession.

³⁵ See Volume II: Evidence, HL Paper 86-II, Page 6

³⁶ See Volume II: Evidence, HL Paper 86-II, Page 138

105. Opinion polls do not suggest any significant anxiety on this score from the point of view of patients—see Chapter Six. In its written evidence the VES pointed to the benefits of open discussion with their doctors of all patients' concerns and wishes relating to the dying process, including the options of assisted suicide or voluntary euthanasia, and to a survey which had reached the conclusion that, out of eleven European countries (including the United Kingdom), the Dutch have the highest regard for and trust in their doctors³⁷. Others pointed to an existing openness of discussion of end-of-life issues here in the United Kingdom. Dr Gilbert told us that, "these sorts of issues about wishing for an earlier death are not terribly uncommon in palliative care practice. Certainly my own experience and that of my colleagues in the south west that I know well would be that such matters do have an opportunity to be discussed openly in trying to concentrate on what are the distressing issues for that patient and those close to them at the time" (Q 2039). Ms Penny Lewis, of King's College London, observed that doctor-patient relationships in The Netherlands were different from those which obtained in the United Kingdom in that most acts of voluntary euthanasia in Holland are carried out by GPs, who tend to know their patients over a long period of time (Q 28). In this country, observed Dr David Jeffrey of the Association for Palliative Medicine, "if you try and register with a general practitioner, you register with a practice; it is a team approach to care. If you call at night, you will get a different doctor, you will not get your own doctor coming to see you... This is becoming less and less likely given the pressures of general practice nowadays" (Q 409).
106. All the medical practitioners who spoke to us agreed that there had been a significant change in doctor-patient relationships over the last 30 years or so in favour of greater openness and patient autonomy. As Lord Walton put it, "The days of 'doctor's orders' are long passed and the practice of medicine is a partnership between the doctor and the patient, in which it is the doctor's responsibility and duty to indicate to the patient what he or she regards as being the best course of action to follow in the management of their condition, but it is up to the patient to decide whether or not to accept that advice" (Q 2045).
107. Lord Joffe recognised the difficulties which legislation in this field caused for the medical profession but cited experience in The Netherlands and Oregon. "We have learned," he said, "that in The Netherlands doctors really worry about assisting patients to die—it is not something they move into enthusiastically and it causes considerable concern. But on the surveys which have been taken in The Netherlands, and certainly in Oregon, the sense is that doctors often feel that actually that is part of their treatment of a patient whom they have known for a considerable time... and they feel that they have done the right thing by their patient. Some doctors might feel that actually they want to be involved: it is part of the treatment for the patient of whom they are very fond and want to assist" (Q 130).
108. What of the effects on the doctor-patient relationship from the standpoint of the doctor? The Royal Colleges of Physicians and of General Practitioners adopted a neutral stance on the principles underlying the Bill. The General Medical Council said in written evidence to us that "we require doctors to obey the law... and our guidance will always be consistent with the law.

³⁷ See Volume II: Evidence, HL Paper 86-II, Page 6 and Q8

Consequently we have not developed a policy or issued guidance on euthanasia... We believe that it is for society as a whole to determine, through its democratic processes, how best to respond to the conflicting wishes of its citizens”³⁸. And Professor Sir Graeme Catto, the GMC’s President, said that, while the Bill would present challenges, “there is nothing inherently present in the Bill that causes problems for the General Medical Council as it exists” (Q 338). Both Royal Colleges however drew our attention to a number of concerns about the Bill itself, and the GMC said in written evidence to us that “a change in the law to allow physician-assisted dying would have profound implications for the role and responsibilities of doctors and their relationships with patients. Acting with the primary intention to hasten a patient’s death would be difficult to reconcile with the medical ethical principles of beneficence and non-maleficence”³⁹.

109. While some of the individual doctors who gave evidence to us spoke of what they felt to be a duty to accompany their patients to the end of their final journey (i.e. they saw assisted suicide and voluntary euthanasia as part of a therapeutic package), others had reservations. Professor Leigh referred to a “sense of great discomfort” among neurologists at taking on this role (Q 1134). Dr Randall drew attention to the ethical need for doctors always to act in the best interests of their patients, irrespective at times of their patients’ wishes. She argued that “patients cannot require a doctor to perform a treatment that the doctor really feels is going to result in overwhelming harm and not benefit. So the parallel is with, say, a patient requesting a surgeon to do an operation where the surgeon says the risks of it far outweigh any possible benefits” (Q 2028). Others felt that acceding to a request for euthanasia implied a value judgement on the part of the doctor of the patient’s remaining life: Dr Gilbert described it as a “psychological push from the bridge, and that moral judgement, which is often expected of doctors, to agree with them that the best thing overall would be for them to end their lives” (Q 2024).
110. Dr Ivan Cox, for the Royal College of General Practitioners, commented that “several of my colleagues feel that there would be a significant erosion of trust in the doctor/patient relationship,” though he added that, “others feel that this is a dynamic and may not change as much as people expect” (Q 224). Dr Wilks believed that there were “many doctors who feel very strongly that you cannot draw a line with autonomy just because it causes you difficulties. You are either autonomous or you are not, and autonomy extends to the point of also being able to decide the time and method of your death” (Q 337). The BMA’s view however was that “legalising assisted suicide would affect some patients’ ability to trust doctors and to trust medical advice”⁴⁰. And Dr Wilks also spoke of the importance, in the wake of recent adverse publicity for the medical profession, of maintaining the public’s trust in its doctors. “I have a concern,” he said, “that re-defining the role of the doctor in the way that this Bill would do might pose some threat to that trust” (Q 334). The majority of the letters we have received from doctors express serious reservations about the impact of the Bill on both their relationship with their patients and the ethics of their profession. It is

³⁸ See Volume II: Evidence, HL Paper 86-II, Page 112

³⁹ See Volume II: Evidence, HL Paper 86-II, Page 112

⁴⁰ See Volume II: Evidence, HL Paper 86-II, Page 110

important also to consider nurse/patient relationships, which the RCN felt could be jeopardised by the Bill (Written Evidence, Paragraph 4.2).

111. In this context some witnesses and members of our committee wondered whether, should a law along the lines of Lord Joffe's Bill be enacted, its implementation should be placed outside the ambit of the health care system. Dr Gill Turner, representing the British Geriatrics Society, questioned why assisted suicide or voluntary euthanasia needed to have medical involvement at all. "People can be given the wherewithal," she suggested, "to end someone's life, but I am not entirely sure why doctors need to be involved, because effectively it is a social decision, not a medical decision" (Q 1196). Dr Turner added that, "if we are trying to de-medicalise some of these decisions... because of the fact that we are talking about people's own autonomous decision-making, then why does a doctor need to be involved?" (Q 1223). Dr Randall felt it would be better, "if society wants assisted suicide and euthanasia, to take doctors out of it apart from establishing the diagnosis, the prognosis and the treatment options for the prolongation of life and the relief of suffering... That way you do not have collateral effects on your doctor-patient relationship. You would not have this problem of elderly vulnerable people worrying about what would happen to them when they were in care" (Q 2018).
112. On the other hand, Dr Nathanson commented: "What doctors find it impossible to consider is who would want to provide that service. They find it almost impossible to conceive of a person who would want to spend their life administering lethal injections. Whether such a service could ever be set up, and who would be the people who took part in it, raises very serious questions" (Q 324). Dr Wilks cautioned that, "the establishment of a separate service is a kind of signal that there is a different group of patients who do not deserve the same kind of overall assessment and communication and discussion about options, and that they can go off to the euthanasia service instead" (Q 325). Lord Walton described this as "a dangerous possibility" which he would not support (Q 2070). We comment further on this issue in Chapter Seven.

Conscientious Objection

113. The Bill provides exemption for persons with conscientious objections to taking any of the actions which it authorises, and we address the detail of this "conscience clause" in Chapter Seven. It has been suggested to us, however, that the Bill, if it were to become law, might well be unworkable because of the conscientious objections of many of those who would be called upon to put it into practice.
114. Dr Ivan Cox, for the Royal College of General Practitioners, warned of GPs opting out (Q 224). The Royal College of Nursing said that "the proposals in the Bill will be unacceptable to many nurses on moral, ethical or religious grounds"⁴¹. Speaking for the RCN, Maura Buchanan drew attention to the high proportion of nurses from overseas within the NHS, many of them with religious objections to what the Bill proposes: she predicted a haemorrhage of trained nurses if the Bill were to become law. We did not, it has to be said, receive indications from the authorities in other countries where legislation of this nature has been enacted that significant problems had been encountered

⁴¹ See Volume II: Evidence, HL Paper 86-II, Page 97

in regard to conscientious objection by large numbers of doctors and nurses, though it is perhaps necessary to bear in mind that the composition of the medical and nursing professions in this country is rather different from that in, for example, Holland, where over 90% of doctors are of Dutch origin⁴².

115. Asked whether the operation of the 1967 Abortion Act did not provide a precedent, our witnesses drew attention to certain differences. Professor John Saunders, for the Royal College of Physicians, believed that abortion and euthanasia were perceived differently by doctors. "The one thing we can all agree on is that, if I give barbiturates or curare to a competent adult, I am killing that person... I do not think anyone can contest that that is killing someone" (Q 246), whereas there was some room for doubt, he suggested, over terminating the life of a foetus. Ms Buchanan drew attention also to a practical consideration affecting the nursing profession. "You can choose not to work in a gynaecological unit, but people die everywhere in health care. So how will you take the nurses and look after them in a nursing home where the local GP comes in to practise euthanasia?" (Q 263)
116. We were also given the results of a survey carried out by the Association of Palliative Medicine (APM). We were told that in the APM survey of its members, which attracted an 84% response rate, 72% percent of respondents had said that they would not be prepared to participate in a process of patient assessment which formed part of an application for assisted suicide or voluntary euthanasia.

Prognosis

117. Terminal Illness is defined in the Bill as "an illness which in the opinion of the consulting physician is inevitably progressive, the effects of which cannot be reversed by treatment... and which will be likely to result in the patient's death within a few months at most"⁴³. Of critical importance therefore is the accuracy with which doctors are able to predict the remaining lifespan of seriously ill patients.
118. The evidence which we have taken from medical practitioners suggests that the prognosis of a terminal illness is far from being an exact science. "It is possible," we were told by the Royal College of General Practitioners, "to make reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months, then the scope for error can extend into years"⁴⁴. Professor Tallis, for the Royal College of Physicians, told us that "medicine is a probabilistic art... In most cases the vast majority of prognoses are right, but there will always be situations where the diagnosis is wrong" (Q 244). Professor John Saunders, also speaking for the Royal College of Physicians, said that "prognosticating may be better when somebody is within the last two or three weeks of their life. I have to say that, when they are six or eight months away from it, it is actually pretty desperately hopeless as an accurate factor" (Q 253). The Royal College of Pathologists drew attention to "a 30% error rate in the medically-certified cause of death", with "significant errors (i.e. misdiagnosis of a terminal

⁴² The Department of Health workforce census for 2003 shows that about a quarter of all doctors practising in the United Kingdom qualified outside Britain or the European Economic Area.

⁴³ Clause 1(2)

⁴⁴ See Volume II: Evidence, HL Paper 86-II, Page 80

illness resulting in inappropriate treatment) in about 5% of cases”⁴⁵. Dr Cox said that, “a doctor deciding that a patient has reached a terminal state is very difficult. In some of the work that I personally have done with doctors on this we have recognised that doctors make arbitrary decisions about when a patient has reached a terminal stage. This can be when the patient is discharged from specialist care, when the patient moves from a curative state to a palliative state; some just use the position when what is known as the DS 1500 Form is actually prescribed, or some just use the point where patients have become bed-ridden or immobile” (Q 224).

119. We put these issues to specialists in palliative care and neurological diseases. In its written evidence the Association for Palliative Medicine had observed that “defining the terminal phase is often much more difficult than people might imagine, particularly in patients with non-malignant disease such as cardiac or respiratory failure”⁴⁶. Asked to enlarge on this during oral evidence, Dr David Jeffery said, “A simple bit of practical evidence is one of the benefit forms that are filled in for patients assigned to the doctor thinking that the patient has six months to live. I would not like to count how many of those forms I have signed in my life for patients still living after a year, eighteen months or even longer... Even in cancer patients it can be very difficult to tell when a patient is dying... The reality in clinical practice is that we can be wrong. I would entirely agree... that this gets easier the closer one gets, but predicting six months is not something that I would like to guarantee to any patient” (Q 388).
120. It is, we were told, even more difficult to forecast the course of degenerative disease (such as motor neurone disease, multiple sclerosis, heart disease or emphysema) than of malignant conditions such as cancer. Professor Nigel Leigh, on behalf of the Association of British Neurologists, told us that “with someone who has severe multiple sclerosis you have a rough idea that they might survive another year or a couple of years but it all depends on other things: whether they get an infection or, for example, septicaemia. You cannot actually judge” (Q 1131). Professor Leigh continued: “We say ‘a few months’ but we cannot possibly judge that in many of the patients we see, and we will end up by perjuring ourselves—or being tempted to—by saying it is a few months when we know it might be anywhere between six months and eighteen months” (Q 1151). Professor Richards of the DoH made a similar point. “Identifying the fact that somebody is actively dying... is quite a difficult thing to do, particularly as given a lot of conditions like heart failure, for example, people can be slowly getting worse but then they have acute dips down, and it is very difficult to know whether they will recover from that particular incident or not... I think that is one of the very difficult things about prognosticating, particularly outside the field of cancer, and knowing how long somebody has got to live” (Q 437).
121. Dr David Cole drew our attention to a WHO Performance Scale used by oncologists in making prognoses of life expectancy. At one end of the scale (0), a patient would be in good health, while at the other end (5), he or she would be dead. In between, Dr Cole said, there were grades showing successive stages in health decline—for example, at Grade 4 a patient would be predominantly bed-bound or in a chair, unable to move or to go to the

⁴⁵ See Volume II: Evidence, HL Paper 86-II, Page 730

⁴⁶ See Volume II: Evidence, HL Paper 86-II, Page 140

lavatory or to eat, drink or wash without assistance. Dr Cole said that he would “feel confident in predicting a very limited prognosis in a patient who was Performance Status 4” (Q 1910). His own experience as an oncologist, said Dr Cole, argued for limiting the provisions of any law of this nature to patients within one or two months of death (Q 1921), though a little later (Q 1925) he adjusted this to “less than three months”. Dr Carole Dacombe pointed out also that patients with an 8-weeks-or-under prognosis received funding for their care from the health sector, whereas those with longer prognoses were funded by social services departments (Q 1964). Professor Tallis suggested that there might be a need to link prognosis with assessment of unbearable suffering. “If the situation is unbearable and the prognosis is that it is going to remain unbearable, then that surely is the absolutely key issue. Clearly that will only happen, usually, within two months of death, but it may be a little longer than that. So I think it is very important not just to confine the notion of prognosis to life expectancy but to expectancy of quality of life” (Q 1924).

122. A further perspective on the subject was offered to us by Professor Timothy Quill, a professor of medicine, psychiatry and medical humanities at the University of Rochester, New York. Professor Quill observed that “when we are trying to prognosticate in heart failure or chronic lung disease... the uncertainty comes because we are still continuing a good amount of disease-directed therapy. If we stop those therapies, people will die much sooner; but the challenge is that they die much more symptomatically if we stop those therapies. We tend to stop them only when they are literally dying” (Q 2122). Professor Quill also told us that, “when a person goes to an acute hospice unit, we are used to prognosticating that they are likely to die within the next two weeks” (Q 2118); and Professor Foley told us that the average time in hospice care in the United States is 14-16 days (Q 2121).

Competence

123. An applicant under the Bill must be competent, which is defined as “having the capacity to make an informed decision”⁴⁷. It seems to us that such capacity encompasses two capabilities—the ability to think clearly and to come to a reasoned decision; and the ability to form a judgement which is unclouded by transient and treatable psychological conditions. The former is, we would say, the easier to assess—in that the attending or consulting physician ought to be able to spot the applicant who is *non compos mentis* or who is not in full control of his or her thought processes. But it is entirely possible for someone with this level of competence to have his or her judgement impaired by depression or despair and to reach decisions which, given time and adaptation to the circumstances of terminal illness, he or she might well reverse. It is these situations which we attempted to explore with expert witnesses.
124. Dr Geoffrey Lloyd, of the Department of Psychiatry at the Royal Free Hospital, told us that “the desire to die covers a spectrum of intent. There are people who express a desire to die in the sense that they would rather not wake up in the morning or they would rather not be here. That is a passive desire to die. At the other extreme there are people who have worked out very careful plans and know exactly what they are going to do to end their

⁴⁷ Clause 1(2)

life, and these people are at extremely high risk. In between those poles there is a spectrum of intent, and far more people express a desire to die than actually make an attempt to kill themselves” (Q 453). According to Dr Lloyd, “all doctors are capable of making decisions about mental capacity when it is fairly straightforward. Those who have had a bit more experience—and general practitioners very frequently acquire training in psychiatry during their general practice training—are able to make these decisions if the case is a bit more complicated. And then, in more complicated cases, that is when psychiatrists, particularly liaison psychiatrists, have an expertise to bring to this area of practice” (Q 473). Mrs Christine Kalus, a clinical psychologist giving evidence on behalf of the British Psychological Society, referred to people “who have episodes of reactive depression as a result of the diagnosis of a life-limiting disease. Estimates vary, but within the population of cancer patients this is thought to be in the region of 25-40% at the time of diagnosis, and similar at other times in the cancer journey—e.g. on confirmation of metastatic disease” (Q 475). Continuing, Mrs Kalus said that “there is a significant incidence of moderate to severe depression and anxiety at various stages throughout the course of many diseases. Measurement of these difficulties is problematic, particularly at the end of life, because many of the symptoms of depression are confounded by the symptoms of disease” (Q 475). Professor Irene Higginson, Professor of Palliative Care and Policy at King’s College London, drew attention to studies carried out in Canada, which suggested that among people with advanced illness the will to live and the desire for death fluctuate throughout the course of terminal illness for all except a very small number of patients (Q 28). On the other hand, the VES drew attention to research which suggested that depression did not play a role in requests by patients in Oregon for assisted suicide⁴⁸.

125. Another aspect of the problem of competence was exposed by witnesses from the Association of British Neurologists (ABN). Professor Christopher Kennard told us that “with a number of the neurological conditions there is a whole issue of cognitive impairment as well. For example, there are patients who to the lay public appear relatively normal but could have severe cognitive impairments and therefore would be unable to give informed decisions in an area such as this” (Q 1127). Continuing, Professor Kennard observed that, “on the face of it most of our patients with motor neurone disease are intellectually intact, very much on the ball and able to make decisions. However, we know from research in our own group as well as internationally that about 30 per cent of those patients actually have significant cognitive, neuropsychological impairment and we do not understand how that impinges on the decision process” (Q 1128).
126. There was a general consensus among our expert witnesses on one point—that the attending and consulting physicians who are envisaged as being effectively the “gatekeepers” in regard to applications for assisted dying could not be expected to spot impairment of judgement in all cases. Mrs Kalus felt that it was “fundamental that any assessment should be the responsibility of the multi-disciplinary team and not a single clinician” (Q 475). Professor Kennard suggested that all applicants for assisted suicide or voluntary euthanasia ought to be assessed by a clinical psychologist or a consultant psychiatrist in order to eliminate mild or moderate depression and to ensure

⁴⁸ See Volume II: Evidence, HL Paper 86-II, Page 5

that the level of competence is sufficient to enable an informed decision to be made (Q 1127). Echoing this thought, Dr Bateman, also for the ABN, considered that there would be a need for “assessment by the consultant in charge of the case, by a psychiatrist, by a neuropsychologist, by a palliative care physician and probably by the general practitioner to make absolutely certain that the consent was informed and was valid” (Q 1130).

Unbearable Suffering

127. “Unbearable Suffering” is defined in Clause 1 of the Bill as “suffering whether by reason of pain or otherwise which the patient finds so severe as to be unacceptable and results from the patient’s terminal illness”⁴⁹. It is sufficiently clear from Lord Joffe’s own evidence to us that, while the patient must make his or her own subjective assessment of unbearable suffering, the attending and consulting physicians must also confirm that this assessment is reasonable (QQ 126, 142 and 144). Witnesses have however raised concerns not only about the definition of “unbearable suffering” but also about the rationale of its inclusion in the Bill.
128. In the view of the National Council for Hospices and Specialist Palliative Care Services (NCHSPCS), “whilst it may be possible for the attending physician, based on a longer relationship with the patient, to assess changes in his level of suffering, such an assessment cannot be made during the course of the single visit to a consulting physician that the Bill envisages, during which all the activities detailed in Clause 2(3) must be undertaken”⁵⁰. Dr Tate, of the NCHSPCS, said that a proper assessment “may take a week or more of knowing the patient and the situation” (Q 364). Dr Wilks took the view that, “what... counts for the doctor is that there is a consistent expression by the patient in a competent, unbiased way, that this for them is an unbearable situation” (Q 349). The Royal College of Physicians suggested that it would be necessary to establish also that an expression by a patient of unbearable suffering did not derive from “unresolved psychosocial issues”⁵¹ which should be identified and treated.
129. Dr Georg Bosshard, a Swiss physician, felt that “physicians have no particular expertise for unbearable suffering” (Q 1924). Baroness Greengross believed that, given that the law if enacted would apply only to competent people, the applicant rather than the doctor must bear the responsibility for the assessment. “With all the safeguards and all the expertise being available,” she said, “it is that person in the end whose view should prevail, because it is about the quality of that person’s life” (Q 1924). Dr Wilks took the view that “unbearable suffering” is necessarily vague because suffering is not necessarily purely physical. The important point is that it is what the patient feels to be unbearable... When we talk to patients about their perception of their illness, it may be very different from the way the doctor might feel the illness is perceived, and it is terribly important to listen to the patient’s view of the impact of their condition on their quality of life and their perception of the value of their continued existence... If on persistent questioning—not just one consultation but on persistent questioning—their

⁴⁹ Clause 1(2)

⁵⁰ See Volume II: Evidence, HL Paper 86-II, Page 132

⁵¹ See Volume II: Evidence, HL Paper 86-II, Page 83

was a consistent belief by a patient that their condition was unbearable, one would accept that they found it unbearable” (Q 349).

130. Dr Randall on the other hand suggested that in many cases, while there could well be unbearable suffering present, it might not derive from the terminal illness but simply exist alongside it. She cited for us what she regarded as a common phenomenon of a terminally ill patient whose spouse had died. “The person who was their source of company and comfort is dead. When they say they are fed up and they wish it was all over and they are asking to be out of this because of their illness—is it the loss of their key relationship? Or are they suffering unbearably as a result of the terminal illness?” (Q 2040). Dr Gilbert pointed out to us that patients other than those who are terminally ill might be said to be suffering unbearably. “There are people,” he observed, “with arthritis who find it unbearable that their lives are restricted by the pain that they have to endure chronically, perhaps for many years” (Q 1974).

The Demand for Assisted Dying

131. In Oregon, in 2003, one in 714 deaths resulted from assisted suicide. In The Netherlands in the same year one in 38 of those who died did so via either assisted suicide or voluntary euthanasia, mainly the latter (the figure is 1 in 32 if cases of euthanasia without explicit request are included). The legislation which permits people to die in this way is, of course, very different in the two countries concerned. In Oregon applicants must be adults and they must be terminal ill, whereas in The Netherlands, though there is a requirement to demonstrate unbearable suffering, there is no requirement for terminal illness and applicants under 18 years of age may qualify, albeit with their parents’ consent. Perhaps most significant, however, is the fact that the Oregon Death with Dignity Act (ODDA) permits only assisted suicide, whereas Dutch law allows both this and voluntary euthanasia—and indeed the latter predominates in practice, accounting for over 90% of assisted deaths in 2003. We shall be commenting in more detail on these figures in Chapter Five.
132. It seems clear therefore that the demand for assisted suicide or voluntary euthanasia, if measured in terms of the numbers of applicants, will vary according to what the law permits. Indeed, it is this which causes most concern to some of the Bill’s critics. They are prepared to accept that, if moral objections to the principle underlying the Bill are laid aside, there could well be a very small number of serious and determined people who are not going to change their resolve and who might be allowed to take their own lives without undue damage to the fabric of society. Professor Leigh, for example, told us in the context of motor neurone disease that “a small proportion of our patients are quite clear that they wish to exercise this option and that preventing them is adding significantly to the burden of suffering... It is a very small minority” (Q 1128). There is a concern however that, unless any change in the law is very tightly circumscribed, others will find themselves pressured in one way or another into taking a course of action which they would not have sought if the law had not allowed it. For this reason we have tried to assess what might be called the “serious” demand for assisted suicide or euthanasia.
133. Lord Joffe suggested to us, in the context that his Bill was intended to cater for terminally ill people for whom palliative care had not provided an answer

to their distress, that it might cover between three and seven percent of patients with terminal illness (Q 101). Mrs Christine Kalus, for the British Psychological Society, told us that “over the years my colleague and I have rarely encountered people who want to end their life, although many express a wish that their suffering was over. Thus, once appropriate symptom control has been achieved in so far as this is possible, people are able to regain some semblance of quality of life. However, it is also important to note that, in our combined experience, there have been very few people, probably less than ten, where there was no evidence of clinical depression or anxiety, their mental capacity being apparently intact, who had an express wish to die and would have welcomed assisted dying, had it been available to them” (Q 475). Professor Leigh, for the ABN, made the same point—that what most terminally ill people want is effective symptom control. “The people who are left over,” he added, “who are not satisfied with that approach, are a very small and very often pro-active group of people for whom the simple burden of the disease—not the dying bit—is what really hits them hard and really makes life intolerable. They cannot bear the continued loss of function” (Q 1151). Dr Carole Dacombe had had the same experience and believed that palliative care specialists must be prepared to listen to such patients (Q 1913). Dr Tom Shakespeare of PEALS believed that: “the people in society who are most keen on this measure are older people, people who are in their seventh or eighth decade, who have had a very vigorous life and who have had control and choice in all areas of their life and really want it at the end of life” (Q 532). It was however also suggested to us by palliative care specialists that others, including patients who have experienced poor symptom control, also make requests for their lives to be ended (Q 387). Professor Foley summed it up as follows: “The question that you need to ask is—are we attempting to cater to a very small population of patients who want control over the end of their life and want physicians to provide that control?” (Q 2116).

Vulnerable Groups

134. We took oral evidence from expert witnesses in regard to the potential vulnerability of two groups of people in the event that the Bill were to become law—the disabled and the elderly.

The Disabled

135. We found a difference of view from, on the one hand, the Disability Rights Commission (DRC) and Disability Awareness in Action (DAA) and, on the other, Dr Tom Shakespeare of the Policy Ethics and Life Sciences (PEALS) Research Institute of the University of Newcastle. The DRC and DAA, while supporting greater autonomy for disabled people and not opposing in principle assisted suicide or voluntary euthanasia for disabled people who could freely choose it⁵², had reservations about how the Bill would in practice impact on disabled people. Their concerns were that the Bill, if enacted, might reinforce existing public prejudices, including those of doctors, with regard to disabled people and that, if assisted suicide and voluntary euthanasia were to be on offer, disabled people might experience subtle pressures to avail themselves of these options and that support for

⁵² See Volume II: Evidence, HL Paper 86-II, Page 220

independent living might become harder to obtain. They did not believe that the Bill offered disabled people real choice or autonomy in the same way that it might do so for those who were not disabled.

136. Ms Jane Campbell, a DRC Commissioner, spoke of terminal illness and disability as being “so inextricably linked that the terms are interchangeable within the eyes of the public” (Q 504). Ms Tara Flood, speaking for the DAA, referred to, “the images that you see on TV, the images that you see in the newspapers, it is the images that people see in hospitals and the images that relatives have seen... it is all those kinds of images that come together to suggest that it is absolutely better to be dead than to be disabled” (Q 514). As a result, said Ms Liz Sayce, Director of Policy for the DRC, “if assisted dying became legal, decisions could be made through a prism of the prejudice and inequity that does still pervade our society” (Q 505). The Bill would not give disabled people real autonomy. In the DRC’s view, it would give “coercion dressed up as choice” (Q 506). “What disabled people want... is a right to a life where we have real choice and control and the protections of that right to life are the same as non-disabled people take for granted” (Q 506). The Bill, said Jane Campbell, “will not increase our autonomy, it will reduce our choice because we will begin to feel the pressure of a culture that would think that actually our choices should be limited” (Q 511). The priority, said Liz Sayce, should be “improved entitlements to services that provide dignity, including palliative care but also very much including social services... This is an imperative so far as we are concerned, to make sure people can make the active choice to live their lives in dignity” (Q 519). Professor Blackburn referred to “the indignity of dependence” (Q 1839). While supporting Lord Joffe’s Bill, he added that “the only objection that I can see... which would carry weight in my own mind... would be the fear that people might feel not necessarily even pressured but a kind of duty to put themselves out of the way, to ask for a release which otherwise they would not have asked for” (Q 1843).
137. Dr Shakespeare saw the matter differently. He felt that it was “inconsistent that the disability community would support autonomy in every other area of life but not the area of choosing when life becomes intolerable to end it” (Q 525). He did not believe that disabled people would be vulnerable to pressure to opt for assisted dying. “I do not think disabled people are dupes... I do not think they are going to be trotted off to die against their will” (Q 532). Referring to the Bill’s restriction to terminally ill people, Dr Shakespeare observed that “terminally ill people could be seen to be disabled, but disabled people are not necessarily terminally ill” (Q 525). And referring to a recent YouGov survey, he concluded that, “only a small proportion [of disabled people] would trust doctors less if the Bill became law” (Q 525). While Dr Shakespeare accepted that many disabled people have had negative experiences of clinicians, he thought such experiences might be exaggerated. “I think the vast majority of disabled people have good experiences of clinicians... I think it is sad that some disability movements think of doctors as the enemy, whereas for the vast majority of disabled people doctors do not always get communication right but they are basically on their side” (Q 526).
138. Lord Joffe himself suggested (Q 522), on the basis of the British Attitudes Survey and the YouGov poll referred to above, that the majority of disabled people supported his Bill. In response Liz Sayce felt that such surveys needed to be treated with caution. She suggested that people with lesser disabilities,

such as being wheelchair-bound, might well favour the option of assisted dying for people with more serious disabilities, such as those with breathing difficulties, with which they personally felt they would not be able to cope. But “people do adapt to each stage... I think it is something like 90% of people with quadriplegia say they are glad to be alive, whereas only 5% of the doctors treating them imagine they would be glad to be alive if they were in their position... I think the people whose views really matter are those people who are in the sorts of positions who are facing these kinds of difficult decisions about possible death, about very significant and long-term impairment” (Q 522).

The Elderly

139. The views we received here showed some similarities with those regarding the disabled. We were told, for example, by the British Geriatrics Society (BGS) that “many older people, probably because of the care that we in the United Kingdom offer them, often feel burdened and often feel a burden to their families, and consequently we are anxious that the choices they make may not truly reflect their wishes but may reflect the way they have been led to feel by the way they are treated within the health and social care system. We feel that older people can be very vulnerable to adverse influence from outside, families and carers, and many of our members have felt that requests to end somebody’s life artificially have usually come from families and carers rather than from the patients themselves” (Q 1173). Help the Aged was also “worried that, if this Bill is enacted, some vulnerable older people might pick up little bits of the story. They might pick up in the same way as they are picking up around ‘do not resuscitate’ stories. This fear of going into hospital—‘What is going to happen to me?’—is a fear that, if they went into hospital, a doctor would have the right to take their life” (Q 1174). And we were told also that, “one main fear is... about going into residential care, not feeling that they have any power over decisions even if the systems try their best to help them to make decisions” (Q 1175). “Many older people,” we were told, “are disempowered in the present system, in the health and care system, very often as a result of poor health and of a general fear of speaking up, or most importantly, simply being unaware what their rights are and what they are entitled to” (Q 1176). On the other hand, Professor Tallis was not aware of evidence “that increasing age is automatically associated with a decline in assertiveness over things that matter” (Q 1907).
140. Asked by Lord Joffe to comment on the results of surveys whose results suggested that some 70% to 80% of elderly people favoured the Bill, Tom Owen of Help the Aged acknowledged that the concerns he had expressed were not shared by the whole of the elderly population. He was however concerned that such polls did not necessarily reflect the views of older people who found themselves experiencing failures in the health and social care system and that, just as older people often complained that the young did not understand what it was like to be old, so many elderly people did not necessarily know what it was like to be very old or infirm (Q 1183). Professor Tallis on the other hand cited evidence from Oregon and The Netherlands to the effect that people over 80 years of age tended not to opt for assisted suicide or voluntary euthanasia. “The older the age of death, the less need in general there is likely to be for assisted dying. Younger people die harder than very old people” (Q 1906).

In Conclusion

141. We have explored in this chapter a number of the key real-life issues affecting the subject of assisted suicide or voluntary euthanasia. We turn now to our findings concerning the experience of legislation of this nature in other countries.

CHAPTER 5: OVERSEAS EXPERIENCE

142. This chapter sets out the evidence which we received when we visited the US State of Oregon, The Netherlands and Switzerland. It includes also a summary of the position in Belgium.

Oregon

143. The Oregon Death with Dignity Act (ODDA) was passed in 1994. It resulted from a Citizens' Initiative, which means that it was proposed by individuals (rather than by the State Legislature) and was voted on by the State electorate. The process was therefore somewhat similar to that of a referendum in the United Kingdom. The ODDA, when enacted in 1994, secured only a narrow majority, being supported by 51% of votes cast. It did not however come into operation for another three years, being held up by a court injunction through which the State Legislature sought to give the voters of Oregon a chance to reconsider their verdict. The ODDA was passed for a second time in 1997 by 60% of votes. It has therefore been in operation for some seven years.
144. The ODDA is similar to Lord Joffe's Bill in that it applies only to people who have reached the age of majority and have been diagnosed as being terminally ill. It differs however in that it does not include a requirement for unbearable suffering and—more significantly—it offers the successful applicant only assisted suicide. This, we were told by Dr Katrina Hedberg of the Oregon Department of Human Services (ODHS),⁵³ "has been defined as taking an oral medication... The only thing that is allowed is a prescription, and in most cases it is for barbiturates that people take themselves orally and swallow" (Q 562). Dr Hedberg felt that the reason for this restriction "was in part because it was perceived that they did not necessarily want a doctor doing something to a patient. That would be an active role that the doctor has, and they thought it might be accepted more if it was patient self-administered" (Q 566).
145. Ms Barbara Glidewell, Director of the Department of Patient Relations at the Oregon Health Sciences University (OHSU), considered that "in the US we are quite a way away in our community dialogue from discussing active euthanasia or injected medication to end life. We are decades away from that" (Q 652). The ODDA, she believed, "fits for us... It is objective and it is supportive of those individuals who choose this" (Q 648). Dr Susan Tolle, of the OHSU Center for Ethics in Health Care, took a similar view. Asked whether other states were considering similar legislation, she answered that some had come close but rejected it. "They parted from it," said Dr Tolle, "but in most cases they [the proposals] included euthanasia as well as physician-assisted suicide" (Q 728).
146. Dr Nick Gideonse, a general practitioner in Oregon, felt that the continuing prohibition of euthanasia was "a political barrier" which served to allay concerns about volition and subtle pressures. "The fact that the patient self-administers in a way that is not easy to do, drinking ounces of a bitter liquid, provides a final piece of clear evidence that this is completely volitional and self-administered". Doctors were also less uncomfortable because "the

⁵³ Equivalent to the United Kingdom Department of Health

physician's role is just one step further back" (Q 849). Ms Barbara Coombs Lee, of Compassion for Dying, a voluntary organisation which supports people who opt to take advantage of the ODDA, agreed. "Having that last firewall, if you will, of having very clear self-administration, in this society, in this state, at this time is important to people, to have that reassurance that it really is a volitional act that a patient must take. The trade-offs are minimal" (Q 849).

147. Assisting suicide outside the terms of the ODDA remains a crime in Oregon. But those who qualify and avail themselves of the Act's provisions are not regarded as having committed suicide. We were told by Dr Melvin Kohn of the ODHS that "by statute these deaths are not called suicide, they are not listed as such on the death certificate and they do not have the ramifications for insurance reimbursement and other kinds of issues that suicides have" (Q 565). Nor, we were told, are autopsies required because deaths under the terms of the ODDA are regarded as "predicted deaths" (Q 957).
148. According to Dr Hedberg, public opinion in Oregon was fairly relaxed after seven years experience of the ODDA. "It is not much of a debate any more because people have seen this has happened in this state but... we are still in double digits. Last year there were 42 out of 30,000 deaths. We have a large number of deaths in our state and very few people participating. It is not that controversial in Oregon, both because lots of people are not participating and because there have not been any really egregious events" (Q 619). Dr Gideonse told us that "it seems to have been assimilated into the social fabric" (Q 839). Dr Robert Richardson, Director of the Kaiser Permanente Ethics Service, said that implementation of the law had showed "that this is not physicians taking charge, this is patients who have taken charge" (Q 855).
149. Nonetheless there remained people who were unhappy about the Act. Ms Glidewell observed that "there are some physicians who are passionately opposed" (Q 630) and that federal and religious health care organisations had declined to offer services falling within the terms of the ODDA (Q 670). Barbara Coombs Lee believed that "there are 20-30 per cent of people whose opinions really are based on their own ethical standards and their own religious beliefs, and those are not moveable. However, there are 30-40 per cent of the population in the middle who are willing to be persuaded, who have fears about abuse and coercion and whether the safeguards actually work and things like that and are persuaded by the Oregon data" (Q 855).
150. The ODHS has the responsibility for recording the rate of uptake of the law, for checking that the basic requirements of the law are being observed and for reporting any discrepancies to the Oregon Board of Medical Examiners (OBME)⁵⁴. It is the responsibility of the OBME, as the regulatory body for the Oregon medical profession, to investigate any apparent irregularities and to decide whether, and if so what, action should be taken on them. The ODHS's role is simply to record what is happening, which includes compiling an annual report giving the number of lethal prescriptions issued and the number actually ingested. The monitoring does not begin, however, until the stage where a patient has been confirmed to be terminally ill (defined as having a life expectancy of six months or less), has made two written requests (separated by a 15-day interval) for assistance with suicide

⁵⁴ Equivalent to the United Kingdom General Medical Council

(as laid down in the statute) and has been issued with a prescription for lethal medication. We were told by Dr Richard Leman, a medical epidemiologist at the ODHS, that “through to the end of 2003 there were 265 prescriptions actually written and 117 people who chose to take them” (Q 577). There has been some increase in the numbers of people who take the prescribed medication—from 16 in 1998 to 42 in 2003, though the number for 2004 was expected to show a fall (Q 558). According to Mr David Hopkins of the Center for Health Statistics, “males and females are equally likely to use the medication. Asians are about three times more likely than whites. College graduates, educated folks, are about seven times more likely than those who have high school degrees. Urban folks are a bit more likely than those east of The Cascades, which is a very rural area, to use the medication” (Q 559).

151. According to Dr Gideonse, “one in six dying patients in Oregon talk with their families about their options and whether they might want to use the Act, one in fifty begin the eligibility process but only one in a thousand eventually use the Act to hasten their death” (Q 839). Many people, we were told, take the prescription but do not use it. They keep it as an “insurance policy”, to be taken if their suffering becomes more than they can bear.
152. We asked whether the figures of reported deaths under the terms of the ODDA could be relied on as accurate. Dr Hedberg told us that “physicians in the State of Oregon have a vested interest. If they follow the steps and report them, they are protected under the law; but, if they carry out actions outside the law, then they are assisting suicide and that is not part of this. We do get pretty good data because, if anything else, it is insurance for physicians to report” (Q 617). Ann Jackson, Executive Director of the Oregon Hospice Association, agreed: “Oregon is a very, very small state and we have hospices all over, and they have big mouths! I think if there were any abuses in the law, we would hear of it” (Q 834). We asked also about any medical complications in those cases where the prescribed medication had been ingested. The OBME had “not heard of any complications of any significance or any complications period. It may be true, but we have not heard them” (Q 929). The OBME had investigated four cases, which appeared to be concerned with procedural aspects, such as a missing witness signature, but had no evidence that serious breaches of the law might be taking place.
153. On the other hand, some witnesses who appeared before us believed that the law was being abused. Dr William Toffler, a general practitioner and a professor at OHSU, said that “every case that we know about, and it is close to a dozen cases now, has serious problems”, among which was “patients who have a known history of depression, only one out of 20 of the patients in the last year got referred for formal psychiatric evaluation” (Q 949). Dr Greg Hamilton, a psychiatrist, told us that medical complications occurred in 15-20 per cent of cases but that these were “not in the records” (Q 955). There was no investigation of deaths under the terms of the ODDA. Ms Karen Bell, a nurse and a director of a Portland hospice programme, told us that “in Oregon, if a patient is terminally ill and dies, one of my hospice nurses can call the medical examiner and the coroner, and all it takes is for the hospice nurse to say ‘This patient has died’. It is not a medical examiner case, there is no autopsy required or anything because it is considered a predicted death” (Q 957). It appeared however that none of these perceived abuses had been reported formally to the OBME for investigation.

154. Oregon, we were told, had good end-of-life care with high enrolment in hospice programmes. There had been significant growth in such services during the last 10-15 years. Dr Tolle told us that in the early 1990s “we had been struggling... to build in-patient palliative care programmes, to strengthen our education on pain management, to expand the use of hospice... Now we are holding 11 major regional conferences, all but one of which has major or total elements of end-of-life education, none of which this year have anything to do with assisted suicide. We have gone from one palliative care programme... to twelve in this State” (Q 684). Dr Tolle cautioned against reading into this growth of end-of-life care a cause-and-effect connection with the enactment of the ODDA (Q 686). “There was,” she said, “improvement under way but the speed of improvement was able to be harnessed. We made a deliberate effort to harness it” (Q 721). Dr Tolle did suggest however that there might be a different connection—namely, that many people had voted for the ODDA because of a tragic experience which a loved one had had in end-of-life care. “In some ways,” said Dr Tolle, “it [the Act] was a vote of no-confidence about some aspects of end-of-life care in Oregon” (Q 689).
155. Hospice care has grown substantially in Oregon as part of the palliative care package. Ann Jackson told us that, “when I started this job in 1988, 2,000 people used hospice in the State of Oregon, and we estimate this was up to 15,000 in 2003, which is 50% of all those who die in the State of Oregon” (Q 807). Ms Jackson also told us that 93% of those who availed themselves of the ODDA were hospice patients (Q 786). “As far as assisted suicide is concerned,” said Ms Jackson, “our position now is that it no longer matters whether we believe it is right or wrong, it is the law of our State and people who are eligible for hospice and eligible for the Death with Dignity Act are one and the same. No Oregon hospice would turn away someone who wanted to use assisted suicide” (Q 786). Ms Jackson also told us that “very few Oregonians use the Death with Dignity Act. Hospice has been offered as the primary explanation for that. People do not need to use assisted suicide because they are in pain or because their needs are not being met in other ways... Oregon has hospice throughout the state... Every Oregonian, in even the smallest community, has access to hospice care” (Q 793).
156. Two observations must, however, be made. First, Oregon has 51 “hospice programmes”, which means that there are 51 programmes for offering hospice care rather than that there are 51 hospices. Dr Tolle told us that nearly 90% of those who die in hospice care in Oregon die in their own homes (Q 686). Ann Jackson told us that “hospice in the United States is provided primarily in the patient’s home, especially in Oregon. Two per cent of our patients die at an in-patient facility or in hospital” (Q 797). Terminally ill patients are able to call on visiting hospice nurses at any time, though those needing 24-hour care would be encouraged to go to an in-patient unit. “We do not have all of the support staff,” said Barbara Farmer, Director of Home Care and manager of Hopewell House Hospice in Portland, “to be able to provide all of our patients with 24-hour round-the-clock care at their bedside. We can do it in short snippets or we have agencies that we work with that can provide the 24-hour care” (Q 804).
157. The second observation is that, unlike in the United Kingdom, hospices in Oregon are for “comfort” care only. As Barbara Glidewell put it, “it pretty much is a one-way ticket opting out into hospice. The hospice teams are paid governmentally for treatments that are comfort-only. You would not come

back to hospital for a CT scan because it would not be paid for" (Q 623). Ms Glidewell gave as an example a hospice patient suffering from pneumonia who "wanted antibiotics for comfort only, not for curative recovery, the hospice group in all likelihood would provide the medication for comfort only but without an exception. Nearly all of our patients who go in... complete a Physician Order for Life-Sustaining Treatment, a POLST form, where they say that they would want comfort measures only, do not resuscitate, no antibiotics except for comfort, probably no artificial hydration or nutrition" (Q 625). Ms Jackson confirmed that entering a hospice involved waiving the right to curative treatment (Q 818). It appears that the reasons for this "difficult disconnect between the curative focus and the comfort focus" (Q 623) are largely financial. To qualify under the Medicare system, a terminally ill patient must gain access to a hospice programme, which itself depends on a prognosis of six months or less of life remaining (QQ 1087-1090).

158. Not surprisingly therefore a linkage has developed between the Act and the hospice movement. Ms Jennifer Traeger, a clinical social worker, told us that "one of the requirements [to qualify under the ODDA] is that the physician has to say that you have six months prognosis, so by virtue of being a hospice patient you have met those criteria. Often physicians will encourage that hospice support as well just to make sure that all of their needs are being met and that the person is not choosing aided dying for some other reason" (Q 805). Ms Jackson also observed that "it is the physician who has the responsibility for writing the prescription. It is the hospice generally who has the responsibility for caring for the patient and making sure their psychosocial needs and their practical needs are being addressed" (Q 794). Such hospice support can extend to pointing patients desiring assisted suicide towards organizations, such as Compassion in Dying, to help them in the event that their doctors decline to participate (Q 794).

159. We were anxious to know how medical practitioners in Oregon viewed the Act. Mr Jim Kronenberg, Chief Operating Officer of the Oregon Medical Association⁵⁵, gave us a very helpful briefing on this. He explained that, though the American Medical Association (AMA) had opposed the Act, the Oregon Medical Association (OMA) "neither supported nor opposed the AMA's position and we neither supported nor opposed the ballot measure" (Q 1022). Mr Kronenberg's summary of the attitudes of physicians is worth quoting at some length;

"I would say there is a small group of physicians... who are adamantly opposed to this measure... There is another relatively small group of physicians... who feel that this is not only appropriate but medically and ethically the right thing to do in certain cases. It is my judgement that the great majority of physicians in this State... perhaps 85% of them are relatively ambivalent about the issue, in many cases because it does not affect them. If you are a radiologist, for example, or an anaesthesiologist... it is something you will never be faced with. It gets down to family practitioners, internists, those physicians whom we look to for our care on a regular basis and then some of the medical and surgical sub-specialities—certainly oncology would be one—who are more likely in the course of their career to be faced with the dilemma of what to do... My experience is that they do not

⁵⁵ Equivalent to the British Medical Association

know what they are going to do until they are faced with the circumstance. Also it is my experience that in the great majority of cases physicians who choose to move ahead do it on the basis of a long relationship with the patient. Typically that would be one's primary care physician, whom they have known and worked with for a long time where they feel they know a great deal about the patient, not only from a medical standpoint but from a behavioural standpoint... Some physicians, even under those circumstances, choose not to participate" (Q 1022).

160. Mr Kronenberg added however that "in my personal experience, the majority of physicians whom I have counselled... who have chosen to talk to me about it, the majority of them chose not to. I think that the majority of those chose to refer to someone else" (Q 1043). Asked whether doctors' attitudes would have been different if the ODDA had included provision for voluntary euthanasia as well as assisted suicide, he believed that in that event the OMA's position "would be the same as it was in 1970, that we opposed it on ethical and moral grounds. It is a very great leap. I think that physicians would feel the same way, that there is an extraordinary difference... in providing someone with the means to end their life and actually ending it" (Q 1048).
161. Dr Richardson, a pulmonologist and critical care physician, felt that "a modest majority of physicians support the right to do some sort of physician-assisted death, although a much smaller proportion are willing to directly participate" (Q 849). Dr Elizabeth Goy, of the Department of Psychiatry at OHSU, considered that doctors were "very uncomfortable" with the experience of being asked to assist with suicide and that "sometimes they are overwhelmed by the impact of this, which is contrary to what they normally do" (QQ 766-7). Ms Farmer observed that physicians "were more willing to refer to the hospice because we were more comfortable with the language" (Q 807).
162. Dr Hedberg told us that "there are some physicians who have come out very vocally as being advocates or proponents of this who have clearly prescribed for many people. I think the majority are physicians who have prescribed once or twice for their own individual patients" (Q 594). Dr Hedberg drew attention also to differences in approach among prescribing doctors. "There are some physicians who look at this and say: 'The patient is asking for a prescription, I will write the piece of paper and they can either fill it or not, but it is giving the patient complete control as to whether they fill it and end up taking it, etc'. We have other physicians who say: 'If the patient is going to make this decision, I want to be involved throughout. I am not going to write the prescription until the patient says to me: 'Doctor, now I really want to take it', and then I am going to be there with them and their family to assist'" (Q 567).
163. What we were told about the typical character traits of those who avail themselves of the ODDA reflects what we had heard from others in the United Kingdom. Ms Glidewell saw them as "pragmatic, matter-of-fact persons who have always been in control of their lives and ordered their lives and want control. I see it over and over as the reason why people say that they want control of their dying process and want to avert having to be cared for in a way that is offensive to them... It is crystal clear to them that they want to name the day, and when they are finished, when life has served them, and enough is enough, they are done" (Q 643). Dr Goy, referring to studies

she had carried out, told us that “most folks said they find being cared for to be intolerable and they have had a lifetime of needing to be responsible and have learned, one way or another, not to depend on others but to be self-sufficient” (Q 753). They tended, she said, to regard religion—though not necessarily spirituality—of little importance and to be “self-confident heading into a great void of nothingness, with no recrimination or retribution for making this choice: they are quite comfortable with it. Typically they do not have a concept of Heaven or the Great Beyond” (Q 774).

164. One of the consequences of a law which permits doctors to prescribe and pharmacists to issue lethal medications is that control of these latter is lost. Though some patients may take the medication when it is issued to them, others do not: they keep it as an “insurance policy”. We encountered some, though not great, concern among our witnesses about this release into the community of lethal substances which could find their way into the hands of others than those for whom they were prescribed. Ms Glidewell told us that “we do lose control of that medication once it is out of our hands. Often we say we can hold the medication for them until they call for it or hold the prescription but not fill it until such time when they are ready, but there is no guarantee they are going to take it then, and you have this lethal dose sitting in the medicine cabinet wondering what they are going to do with it” (Q 735). The ODHS assumed that, as most people who take their own lives under the terms of the ODDA are participating in a hospice programme, the hospice took care of unused medication. But, added Dr Hedberg, we do not have a way to track, if there was a big bottle sitting in somebody’s medicine cabinet and they died, whether somebody else chose to use it” (Q 591).
165. We conclude our summary of the situation in Oregon with an interesting observation from one of our witnesses, Dr Peter Rasmussen, an oncologist. He contrasted the situation in other parts of the United States—where (he claimed) patients were often given aggressive treatment for terminal conditions, where death was often viewed as a defeat and where in consequence death often occurred in hospital intensive care units—with that which obtained in Oregon, where (as recorded above) some 50% of those who die are in hospice programmes and therefore receiving “comfort-only” care. Now, said Dr Rasmussen, “we have more home deaths in Oregon than in almost any other place in the nation. Our populace has been there. Our populace has stayed up nights caring for their loved ones as they were dying, whereas in other parts of the country their experience of the death of a loved one is from a waiting room in an intensive care unit” (Q 855). Given the high level of hospice-in-the-home care in Oregon, this strikes us as a relevant observation, though Dr Rasmussen’s conclusion—that “that may be applicable for the United Kingdom, because I think you have more home deaths and you are probably closer to Oregon’s experience” (Q 855)—is perhaps open to question.

The Netherlands

166. The history of assisted suicide and voluntary euthanasia in The Netherlands is very different from that in Oregon. Though a law legalising these practices has only recently been passed by the Dutch parliament⁵⁶, the criminal and supreme courts of the country had since 1973 adjudicated on a number of

⁵⁶ The Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002

cases where defendants had invoked—usually successfully—the defence of necessity against a charge of murder. This defence was explained to us by Mr Jakob Kohnstamm, of the NVVE⁵⁷, as being “the situation where you have an ethical or moral dilemma between, on the one hand, someone’s request which you feel is an honest and honourable request and, on the other, something which is prohibited by law, [so that] in certain circumstances you are acquitted. It is not that it is not criminal: it remains a criminal act, but you will not go to prison for it” (Q 1547).

167. As a result, the 2002 Act was effectively a codification of existing practices which had been built up on a basis of case law. According to Dr Rob Jonquiere, also of the NVVE, this had been “a great advantage of the Dutch situation. After the legalisation was completed, the practice did not change greatly”. What did change, said Dr Jonquiere, was that assisted suicide and voluntary euthanasia now became “a legalised option for doctors and patients, but in terms of the process it did not change greatly” (Q 1541). The purpose of moving from case law to statute law, we were told, was to remove the uncertainties, for doctors and patients, which had surrounded earlier adjudication of cases brought before the courts.
168. There is a key difference between the 2002 Dutch law and the 1997 law in Oregon: Dutch law permits voluntary euthanasia as well as assisted suicide. We were told that the medical profession in Holland makes no moral or ethical distinction between the two. Dr Johann Legemaate, of the KNMG (Royal Dutch Medical Association), said that “many doctors prefer euthanasia for practical and clinical reasons, because when it is assisted suicide you hand over the medication to the patient and he has to take it himself. It may have side effects which will lead to the doctor acting anyway. For that reason most doctors prefer euthanasia” (Q 1233). This was, he said, notwithstanding guidelines from the KNMG to the effect that assisted suicide was preferable to voluntary euthanasia “in the psychological sense for the doctor and in the sense that it emphasizes a little more the responsibility of the patient” (Q 1234).
169. Euthanasia is defined in The Netherlands in a highly specific way. In Dutch law, the term “euthanasia” includes also what we term in this report “assisted suicide”. On the other hand, it specifically excludes the ending of a person’s life without his or her request. In other words, the Dutch do not recognize the existence of involuntary as well as voluntary euthanasia: while the latter is now permissible in law, the former is regarded as murder⁵⁸ (Q 1247). The Dutch definition of euthanasia also excludes specifically the withholding or withdrawal of treatment, whether or not at the patient’s request, and the administration of pain relief by a physician with the possible side-effect—but not the intention—of hastening death. In this respect the Dutch definition mirrors that which obtains in the United Kingdom.
170. The 2002 law is not limited to adults. Nor does an applicant for euthanasia have to be terminally ill. As Dr Legemaate put it, “the main basis is hopeless and unbearable suffering; it has nothing to do with your life expectancy”. He added however that “in actual practice I think that our law is very close to

⁵⁷ The Dutch equivalent of the United Kingdom Voluntary Euthanasia Society

⁵⁸ For these reasons, when discussing the situation in The Netherlands we use hereafter the term ‘euthanasia’ to mean voluntary euthanasia only and to include assisted suicide as well as action taken by a doctor directly to end a patient’s life.

your Assisted Dying Bill, in the sense that 95% or 98% of the cases... are patients within the last days or weeks of their life... But we do not exclude the rather exceptional situations in which, for instance, somebody who is 55 and has a very severe but incurable mental illness—which relates to a situation of hopeless and unbearable suffering—asks for assisted suicide. We have had these cases every now and then. Not many, but they are not excluded” (Q 1285).

171. Approximately 16 million people live in The Netherlands, of who around 140,000 die every year. We were told that some 9,700 requests for euthanasia are made annually. About 3,800 of these actually receive euthanasia, of which some 300 are assisted suicides. Euthanasia therefore accounts for around 2.5% and assisted suicide 0.2% of all deaths in The Netherlands. In addition to these, there are about 1,000 deaths a year (0.7% of all deaths) where physicians end a patient’s life without an explicit request⁵⁹.
172. Under subsection 2 of the 2002 Act a Dutch physician who carries out euthanasia is exempt from prosecution if he fulfils a number of specified criteria of “due care” and notifies the coroner. There are six such criteria. The patient must have made a voluntary and well-considered request to die; his suffering must be lasting and unbearable; he must have been informed about his medical condition and prognosis; both the doctor and the patient must be satisfied that there is no other reasonable solution to the situation; the doctor must consult at least one other (and independent) physician, who must visit the patient and give his written opinion of whether the requirements of due care have been met; and, finally, the doctor must terminate the patient’s life with due medical care. The “second opinion” is now increasingly provided by a team of SCEN (Support Consultation Euthanasia Network) doctors. We examine this system in more detail below.
173. Once the patient has died, it is the doctor’s responsibility to report the death to the coroner and to complete a report. The coroner visits the place of death, performs an external medical examination of the patient and notifies the public prosecutor and the civil registrar⁶⁰. He then compiles his own report, noting the cause of death, and forwards this, together with the doctor’s report and, if necessary, the patient’s medical notes, to one of five regional assessment committees.
174. The committees were set up under the 2002 law. We were able to discuss their operation with the committee covering The Hague. Its chairman, Mr Jan Suyver, told us that “the committees investigate each reported case and assess whether or not the criteria are met with. It is black or white, not grey. However, in its written explanation on its judgement the committee is entitled to mention all the relevant circumstances and dilemmas... If the committee finds all the criteria fulfilled, then the case is over—end of the story. There are no further investigations, no prosecution. If not, the committee must also notify the public prosecution service and the health inspectorate⁶¹. The committees do not give advice on whether or not to prosecute or to bring the case before a disciplinary tribunal. Those are the exclusive decision powers of the prosecution service and the health

⁵⁹ See Volume II: Evidence, HL Paper 86-II, Page 393

⁶⁰ Equivalent to the United Kingdom Registrar of Births, Marriages and Deaths

⁶¹ Equivalent of the United Kingdom General Medical Council

inspectorate” (Q 1439). The committees do not have a role in monitoring euthanasia practices. Dr Gerrit Kimsma, the physician member of the committee, told us that they “have data on the variety in numbers [of euthanasias performed] between physicians, but we do not keep track” (Q 1455). There is thus no routine procedure which would show whether some physicians are performing significantly more euthanasias than others, though it would be possible, we were told, to “put it a query” and extract this information (Q 1457).

175. The role of the regional committees is therefore to assess whether the “due care” requirements have been met. In doing so, we were told by Dr Kimsma, “we must be sure there has been no manipulation, no pressure or undue influence, and that the request is well considered. It must have been expressed and dealt with several times, sometimes years before the actual date of the euthanasia or assisted suicide. The wishes preferably must be supported in writing. This is not exactly a legal condition, but it certainly helps and makes the assessment simpler. The assessment of unbearable suffering without the prospect of improvement is one of the difficult issues of the committee’s assessment. What does “unbearable” mean? It has a very subjective patient-related side, but it must always be a joint conclusion. In order for a physician to come to the conclusion that euthanasia is an option, there should be a joint, shared process of decision-making, where the physician also has to be very much in conformity with the wishes of the patient” (Q 1441). Commenting on the SCEN system for obtaining second opinions, Dr Kimsma said: “It is now legally possible that a physician without any training can do a consultation, but what we see in the committee is that those consultations on paper are inferior. The consultations of the SCEN, the specifically trained physicians, are much more adequate and much superior” (Q 1441). Dr Kimsma added that “there is an absolute condition that [euthanasia] can only be done by the treating physician. It cannot be any other physician. We do not want to advertise ‘euthanasia tourism’. What we insist on is that it only takes place within a meaningful medical relationship. That is an absolute condition” (Q 1441).
176. We have referred above to the SCEN project, under which doctors can receive training in the operation of the law and in the problems with which general practitioners can be faced when a patient requests euthanasia and can volunteer to be available to provide second-opinion consultations in specific cases as they arise. According to Dr Legemaate, SCEN “aimed at professionalising the independent consulting physician”. Dr Tjonne de Graas, a nursing home physician who is also a palliative care specialist and a SCEN doctor, told us that “SCEN physicians are a special breed, with special training for a very delicate task”. There were, he said, three reasons for the launching of the project. The first was to give doctors confronted with a euthanasia request the opportunity to make contact with an independent and experienced colleague who could provide medical and emotional support to the doctor’s thought processes. “Because of our training we can, with the physician, draw the complete context of the request for euthanasia, hopefully also to clarify some aspects that may be overlooked in such stressful and extraordinary situations” (Q 1712). The second was to carry out a second-opinion consultation, as required by the law; and the third was to provide encouragement to doctors who carry out euthanasia to report their actions. “Because of our training,” said Dr de Graas, “and also because of our experience and the countrywide availability of SCEN physicians, this

guarantees a uniform and independent view and... control of the procedure” (Q 1712).

177. This view of the SCEN project was echoed by others. Dr van Coevorden, a GP and SCEN physician, believed that SCEN had the advantage of “not only checking if things are going exactly according to the law but also being of personal assistance to a doctor who may have problems during this process” (Q 1349). Dr Maria van den Muijsenburgh, a GP and palliative care specialist, felt that SCEN provided helpful “backing against pressure” on doctors from relatives (QQ 1482-3). The project, said Dr Legemaate, had so far been focused on GPs, because that is where most requests for euthanasia are both made and carried out; but it is now being extended to physicians in hospitals and nursing homes. In a year or two there would be “100 per cent coverage of all euthanasia situations in this country” (Q 1252).
178. Having set the Dutch scene, we turn now to consider some of the specific issues which we found. The first is the disclosure that there are around 1,000 instances every year in The Netherlands of a patient’s life being ended by a doctor without an explicit request. (See Paragraph 171). Dr Legemaate’s written evidence on behalf of KNMG stated that “this happens mostly with patients suffering from cancer in the last days or hours of their life”⁶². Dr van Coevorden, on the other hand, told us (Q 1310) that “it involves ending life without request, but it is outside the scope of this discussion because it involves newborn children, with defects and so on”; and this view was echoed by Mr Jacob Kohnstamm, Chairman of NVVE, who said “they are, for example, in neonatology, severely handicapped new-born babies—problems that are mainly in the medical sphere” (Q 1607). However, we received yet another account from Ms Irene Keizer, a Senior Policy Officer of the Dutch Ministry of Health, Welfare and Sport. “There are some cases,” she told us, “in which it is not careful euthanasia, but in most cases are people who are not able to make a request because they are not seen as able to make a request—for instance, people who are suffering from a psychiatric disease or people who are in a coma. Also newborn babies are not capable of making a request” (Q 1420). When asked what proportions of the total might consist of people in these various categories, Ms Keizer thought that about half of them were people not capable of making a request (e.g. they were in a coma), “25% are people who could have made a request but did not (so we are wondering about those), 15% are newborn babies, and 10% are other categories” (Q 1422).
179. Yet another perspective was given to us by Professor Gerrit van der Wal, Head of the Department of Public Health at the EMGO Institute in Amsterdam. “Roughly speaking,” said Professor van der Wal, “in about half of all those cases there has been some kind of discussion before the patient became incompetent... but not an explicit request for euthanasia. Almost all patients—in our last study 100% of all patients—were incompetent at the moment of decision... It is about patients who are mostly very ill, dying and seen to be suffering very much, by vomiting their stools, having very bad bedsores, severe dyspnoea and suchlike. As we also know from qualitative studies, doctors feel that they have their back against the wall; that the family and nurses are asking him or her to end this suffering and this unbearable state of life; and then they decide to hasten the end of life. Whether or not

⁶² See Volume II: Evidence, HL Paper 86-II, Page 393

this is very explicit is not that clear. For example, we found that the drugs used in these kinds of cases are mostly opioids, as used for intense pain and symptom treatment, and not neuromuscular relaxants as used in euthanasia. We are neutral researchers, but we do not like these cases... We hoped that they would decrease in number, but it has not happened" (Q 1699). Professor van der Wal said that, "so far as we can see, there is no association between the development in jurisprudence and law and life-ending cases without a request" (Q 1683).

180. The second issue which we addressed with several of our witnesses is the rate of reporting by doctors to the authorities of euthanasias which they have carried out. We will not examine here in detail the somewhat complex methodology by which the latest figure (54% of all euthanasias being reported to the authorities) is arrived at. The questions on which we have focused are: how reliable is the quoted 54% reporting rate? And why do doctors not report?
181. Dr Agnes van der Heide, a senior researcher at the Erasmus Institute, Rotterdam, believed that the wording of the research questionnaire which was sent to doctors was insufficiently precise and that this had resulted in an inadvertent over-stating of the number of euthanasia cases. "We asked physicians," she said, "the following question: Did you provide in this case a drug with the explicit aim of hastening the patient's death? And, if you did so, did you do this at the explicit request of the patient? If both questions were answered positively with 'Yes', then we classify this case as a case of euthanasia. This is meant to be an objective classification scheme for euthanasia, but at the same time it means that our definition is not always similar to the physician's definition. When the physician answers both questions 'Yes', it is not that in all cases the physician himself defines the case as one of euthanasia" (Q 1630). Dr Jon Bos, a surgical oncologist, believed that, if such misunderstandings were removed, the reporting rate might rise to around 85%. On this basis, though Dr Bos did not adduce any hard evidence to support his 85% figure, some 600 instances of actual euthanasia might go unreported in The Netherlands annually.
182. We were unclear why, given that one of the conditions of immunity from prosecution under the 2002 law is that cases of euthanasia are reported, some doctors did not do so. Dr Bregje Onwuteaka-Philipsen, an Associate Professor at the Free University of Amsterdam, believed there were three reasons. "There are people who still do not want the administrative bother of it, or the idea that you report it. There are people who think that you should not report it, either because they feel that it is not really euthanasia or because it is something between the doctor and the patient. It is also possible that there are people who perhaps doubt whether the case would go through easily—whether they have exactly fulfilled all the requirements" (Q 1626). Others gave a similar picture—see for example QQ 1337, 1409, 1434 and 1462. Dr Bos felt that, if his 15% figure of unreported cases were valid, "those 15% may be the doctors who are afraid to report because they fear prosecution or whatever... Sometimes the rules may prevent you from helping your patient; going by the rules might sometimes mean letting the patient down. That could also be the case in some of those 15%" (Q 1337).
183. The third issue which we examined during our visit to The Netherlands was the state of palliative care in that country and its relationship, if any, with euthanasia. We were told that there had been a substantial investment in

palliative care, as a result of which palliative care departments and regional specialist teams had been created throughout the country; and that more resources were being devoted to raising palliative care standards in nursing homes and care homes (Q 1362). “The underlying principles of the policy,” said Dr Cilie Alberda of the Ministry of Health, Welfare and Sport, “are integration in a regular health care system, improving access to and availability of palliative care. The approach is generalist... This means that all GPs and nurses must have been trained to give palliative care” (Q 1362). What this means is that palliative care is not recognized in The Netherlands as a clinical speciality. Dr Alberda said that this generalist-only approach was adopted because most people in Holland die at home: there were specialists in the regional consultation teams, from whom GPs and nurses could, if necessary, obtain advice (QQ 1367-69). According to Dr Ben Zylicz, a hospice medical director, the result was that hospitals in general were “totally devoid of input from palliative care specialists” (Q 1515).

184. Dr van Coevorden felt that there had been “an enormous boom” in the past few years in palliative care training and in hospice care, which he felt had been stimulated by the law on euthanasia (Q 1304). Accepting that palliative care had been at a low level, he believed that in the last five years it had come up to a very high level (Q 1305). Dr Zylicz told us that “many GPs now, knowing the basics of palliative care, can better resist the pressure from the family if they can offer something instead of euthanasia. We have also seen the number of euthanasia requests in hospices really decrease in the last years” (Q 1484). Patients entering hospices who request euthanasia were increasingly withdrawing those requests when palliative care was provided (Q 1510). On the other hand, said Professor Henk Jochemsen, a medical ethicist, the number of euthanasia requests in the population at large was not decreasing (Q 1510).
185. Having said that palliative care in Holland had come up to a high level, Dr van Corvoerden also told us, when explaining later in his evidence why people in The Netherlands asked for euthanasia, that “84% of them have pain; 70% have extreme fatigue; 50% have gastrointestinal complaints and loss of weight; 70% have coughing, dyspnoea or suffocation; almost 70% feel extremely weak. Each of these symptoms or combination of symptoms may lead to a situation that, for these patients, is unbearable suffering and unacceptable, and that is basically the reason why they ask their GP to have their life ended” (Q 1325). Dr van den Muijsenburgh and Dr Zylicz also told us that, whereas there had been an increase in funding in the late 1990s to accompany discussion in parliament of euthanasia legislation, that funding had now ceased (Q 1491). And Professor Jochemsen suggested that the funding which had taken place had not produced a growth in the quality (as distinct from the quantity) of palliative care. “Since there was a lot of money at the end of the 1990s and the beginning of the century,” he said, “many institutions which were providing nursing care in general were opening palliative care units, because they got more money for the patients. The number of palliative care units has therefore increased considerably, but these people are mostly just continuing what they were doing—in the sense that there is no real specialist understanding, knowledge and practice of palliative care... So the number of places where palliative care is offered does not say very much about the quality of palliative care in general in The Netherlands” (Q 1536).

186. During our visit to The Netherlands we visited Sint Jacob's Hospice in Amsterdam. This is a nursing home and a home for the elderly, in which 450 people are currently living. It has wards for medical and psycho-geriatric care and for rehabilitation, plus a stroke unit; and five years ago it opened a palliative care unit (Q 1711). Effectively, therefore, St Jacob's provides a hospice facility within a broader establishment for care of the elderly.
187. Though St Jacob's has grown out of a religious foundation, it has not set its face against euthanasia. We were told however that, though the question of euthanasia has been raised on a number of occasions within the hospice, it has only taken place on one occasion in the last five years (Q 1711). The reason given for this was that the quality of palliative care in nursing homes was now "at a very reasonable level" (Q 1728) and, perhaps more important, that there was a difference in character between those who died in nursing homes and those who died at home. According to Dr Roeli Dijkman, President of the Dutch Society of Nursing Home Physicians, "patients who suffer from terminal illnesses make the request for euthanasia before they go to the nursing home. In principle, the patients who ask for euthanasia have a vision of dying and losing their dignity" (Q 1742). He told us also that "when you have a terminal illness at home and you do not want to die by fading away, with palliative care, you decide to have euthanasia at home. Most euthanasias are by general practitioners" (Q 1728). Dr Dijkman's view is consistent with what we were told by Dr Onwuteaka-Philipsen (Q 1668)—that, while euthanasia accounts for some 2.7% of deaths overall in The Netherlands, it accounts for 5% of deaths under the age of 65, 3.3% of deaths between the ages of 65 and 79 and 1.4% of deaths over the age of 80.
188. We were shown an example of a "euthanasia statement" which the NVVE offered to its members⁶³. The object of such statements is to help people who so wish to state in advance that they would not wish to continue to live if at a future date they should find themselves in specified conditions. As such, these statements could be said to have similar objectives to what we would term "advance directives" in regard to such matters as resuscitation. The example of the statement which we were shown requests a physician, if the signatory should be in a state of "unbearable suffering" and/or "a condition which provides little or no prospect of a return to what is for me a reasonable and dignified existence," "to fulfil my death wish by allowing me to take substances under his or her supervision—or, if I am no longer able to do so, to administer to me substances—that will bring about a mild death". The statement lists a number of conditions, which signatories are invited to tick as they regard appropriate and which might be included under the headings of "unbearable suffering" or "reasonable and dignified existence". These include, in addition to such states as "a life with serious, permanent paralysis", other conditions such as "being blind or virtually blind and/or deaf and/or virtually deaf which make it impossible or virtually impossible for me to perform what are for me worthwhile activities such as reading, writing, watching television, listening to music and doing manual work or handicrafts" and "having a severe impairment or continuing degeneration of my mental faculties, as a result of which I... must be confined because I would otherwise go wandering".

⁶³ See Appendix 6

189. Commenting on the statements, Dr Jonquiere of NVVE said that “we try to help our members to formulate what in their view is unbearable. The identification of what is unbearable is for the patient. They are the person who says ‘This suffering, for me, is unbearable’. This helps them to formulate what is unbearable. But ‘unbearable’ alone is not sufficient to come to the conclusion that euthanasia is the solution. There you need medical expertise in terms of the hopelessness of the suffering. It is those two people—the doctor and the patient—who come together, to compare and discuss, deal and wheel—whatever you may call it—about the unbearability and hopelessness” (Q 1557). Dr Jonquiere made clear to us that the presence of such a statement does not mean that euthanasia will follow automatically if any of the specified conditions should develop; it is simply a request, and the physician must satisfy himself that there is “unbearable suffering” also (Q 1566). Asked about what might happen in the event of a signatory becoming unconscious as well as having reached one of the specified conditions, he replied that, “when a patient is unconscious, it is something which in practice is presently considered not to be compatible with suffering, and so not a reason for euthanasia” (Q 1558).
190. Finally, we sought to form a view of how legalised euthanasia is regarded by Dutch doctors and Dutch society as a whole. Ms Keizer of the Ministry of Health, Welfare and Sport said that “we have asked doctors what they think about the law and whether they think that it is an improvement. They think that the procedure improved after the law came into force. The review committees are working fast and are giving clear judgements. Doctors also expect that there will be more transparency and that the willingness to report will improve” (Q 1396). Dr Legemaate, for the KNMG, told us that, “a large part of the medical profession finds it acceptable that there is, in our society, the possibility of euthanasia. 20% to 25%... are opposed, mostly for religious reasons and also on some non-religious reasons—for instance that it is not compatible with their medical oath or the medical profession” (Q 1237). For society as a whole, according to Dr Legemaate, “there has been a kind of increasing acceptance of doing euthanasia, which I think incorporates a certain change of opinion about the moral aspects and how you balance that” (Q 1250). And Dr Onwuteaka-Philipsen told us that opinion polls suggested that “92% think that it is good that a doctor will no longer be prosecuted for euthanasia, if all the requirements are met. 91% think there should be control on euthanasia” (Q 1659).
191. On the other hand, Dr van den Muijsenburgh reported that in research which she herself had carried out, while doctors were willing and capable of administering intense and very personal palliative care that met the needs of their patients, there was a considerable variation among physicians in regard to the incidence of euthanasia. While most doctors, she said, were supportive of their patients, “there were... doctors who were very willing to commit euthanasia—doctors who themselves thought ‘Suffering is useless’—and more than half of their patients die by euthanasia” (Q 1537). And Dr Zylicz cautioned against acceptance at face value of opinion polls which suggested that there was a high level of public support for euthanasia. The result, he felt, depended on the question which was asked (Q 1502). Dr Zylicz agreed, however, with the statement that there had been no slippery slope and that some patients, whose physical symptoms appeared in the eyes of their doctors to be properly controlled, persisted with requests for euthanasia (Q 1508).

Switzerland

192. The legal position of assisted suicide and voluntary euthanasia is different in Switzerland from that which obtains in both Oregon and The Netherlands, though it is closer to the former than to the latter. Article 114 of the Swiss Penal Code makes the killing of a human being “upon the latter’s earnest and urgent request” a criminal offence punishable by imprisonment. Voluntary euthanasia is therefore illegal. Article 115, however, prohibits incitement to and assistance with suicide if the guilty party acts from self-serving ends but exempts those who act from entirely honourable motives, such as assisting suicide in order to help bring an end to suffering. The situation in Switzerland differs also from the position in Oregon and The Netherlands in that assistance with suicide is not regarded as the exclusive province of doctors. Anyone may legally give such assistance from non-selfish motives. Where lethal medication is required, a doctor’s prescription is needed for this to be obtained, though this requirement exists in order to ensure control of dangerous drugs and not because of a view that assistance with suicide is a function of medicine.
193. Another difference in the Swiss situation is the involvement of voluntary organisations. There are three main organisations in Switzerland involved in assisting people with suicide—EXIT, which has a membership of some 50,000 and which caters for the German- and Italian-speaking regions of the country; AMD, a parallel (and smaller) body dealing with the French-speaking areas; and DIGNITAS, a recently-founded break-away group from EXIT with a membership of some 4,500, which provides assistance with suicide to foreign nationals travelling to Switzerland for the purpose as well as to Swiss citizens. The active help which these organisations provide to applicants, including medical examinations and facilities for suicide to take place, is a distinguishing feature of assisted suicide in Switzerland.
194. Switzerland is a highly federal country, with day-to-day government and administration devolved to the cantons. The laws governing assisted suicide and voluntary euthanasia, however, are federal in nature and apply to Switzerland as a whole, though their application is a cantonal responsibility. These laws, which were written in 1937 and introduced in 1942, were not enacted specifically with terminally ill people in mind but were rather a codification of the legal systems which had existed previously in the cantons. The application of assisted suicide as means of dealing with the suffering of terminally ill people was a dimension which, we were told, emerged in the 1980s.
195. The Swiss Penal Code does not regulate assistance with suicide otherwise than to prescribe that such action should not be self-serving. We were told by the Federal Ministry of Justice that the definition of “self-serving ends” in assisting suicide had been clarified by successive tribunals and included such situations as that of a person who gave such assistance “to satisfy his own material or emotional needs... the possibility of eliminating some major problem for the family, or other motives such as gaining an inheritance, relieving himself of the burden of supporting the individual... or eliminating a person he hated” (Q 2135).
196. The Swiss authorities appear to have concerns about some aspects of the present law, in particular regarding assistance with suicide being given to foreigners coming to Switzerland for the purpose—for the Swiss Penal Code, unlike its counterparts in Oregon and The Netherlands, does not restrict

legal assistance with suicide to persons living in Switzerland. Dr Andreas Brunner, Attorney-General of the Canton of Zurich, was concerned about situations where “a person comes today and dies the same day” (Q 2269), since this inevitably precluded the building-up of a proper relationship between a terminally ill person who is assisted to take his or her own life and the doctor who assesses the case. There have been a number of proposals put forward in the Swiss Parliament to combat such “death tourism” (Q 2127); and, though each of these has so far been either rejected or abandoned, we were told by Mr Bernardo Stadelmann of the Federal Ministry of Justice that the Swiss authorities were aware of the problem and that the Government was trying “to ascertain whether there is a danger of the situation in Switzerland being exploited and, if so, [it would] take appropriate steps to remedy the situation” (Q 2127).

197. Because the Swiss Penal Code does not link assisted suicide specifically with terminal illness or suffering as the result of ill health, it does not specify any medical conditions under which assistance with suicide may be given: it requires simply that the motivation of the person giving assistance shall not stem from self-serving motives. However, the Swiss Academy of Medical Sciences (SAMS) has drawn up a set of medical ethical principles governing end-of-life care, as part of which guidelines have been established for use in situations in which doctors may be asked to assist a patient to end his or her life. The SAMS guidelines prescribe that “physician-assisted suicide is not part of medical practice” (Q 2178). They go on to state that, while a doctor’s primary role is to alleviate symptoms and to support the patient, there may be situations in which the patient asks for help in committing suicide and persists with this wish. In this dilemma, between established medical practice and support for his patient’s wishes, the doctor may either refuse to comply with the patient’s request or accede to the request provided that he is satisfied that three conditions have been met—that the patient’s state of health makes it clear that he or she is nearing the end of life; that alternative possibilities have been discussed and, if desired by the patient, implemented; and that the patient who requests help to end his or her life is capable, free from external pressure and has thought through his or her decision. The Academy recommends also that, in such situations, a third person should verify that the third condition has been met.
198. In fact, the majority of assisted suicides which take place in Switzerland are not directly supervised by doctors. Most people who are assisted to commit suicide are members of one or another of the country’s “suicide organisations”. The development of these organisations was explained to us by Dr Brunner. He told us that, “when the law was made, we did not have any suicide organisations... In the late 1980s the first suicide organisation was established. That was EXIT... Now we have five or six organisations and some splinter organisations too. Then, in about 2000, suicides of people from England started” (Q 2252).
199. The increase in the number of suicide organisations seems to be matched by an increase in the number of assisted suicides in Switzerland. According to Mr Stadelmann, up to 1993 EXIT assisted about 30 cases a year. “Since 1993 we know that there have been about 100 cases a year” (Q 2128). The figures for DIGNITAS, he said, followed a similar trend. “They declared three cases in 2000, 37 or 38 cases in 2001, about 55 cases in 2002... and 91 cases in 2003” (Q 2128).

200. Because the role of suicide organisations is such a unique feature of assisted suicide in Switzerland, we took evidence from two of them—EXIT and DIGNITAS—during our visit to the country. These two organisations have quite different internal structures. EXIT is managed by an annually-elected board of five people, who are supported by an ethics commission (which considers the handling of difficult cases) and a compliance commission (which ensures that the association's rules are followed). DIGNITAS on the other hand is a much smaller body, controlled by a two-man board and with a doctor and lawyer to give supporting advice.
201. The team of witnesses whom we met from EXIT emphasised that they took their work conscientiously. According to Dr Klaus Hotz, EXIT operates “conditions for assisted suicide [which] are much higher than the penal law... We must firstly have a poor medical prognosis, unbearable pain or substantial impairment. The full discretion of the person committing suicide is the second part” (Q 2401). There is, however, no requirement on the part of EXIT that the patient will otherwise die a natural death within a specific time frame. “For us,” said Dr Hotz, “the autonomy of the person is in a way our first point of view. We are rather liberal on this medical prognosis” (Q 2404). And, according to Dr Giancarlo Zucco, there has been “a change of philosophy because in the beginning EXIT was only prepared to assist people who were terminally ill or had very strong pains or were disabled, for instance... Recently it has been decided that we would also assist elderly people who simply decide that they do not see any meaning in their life any more”. (Q 2428)
202. If the existence of organisations which give assistance with suicide is an unusual feature of the Swiss scene, DIGNITAS represents an unusual feature within these organisations by offering assistance with suicide for foreign nationals travelling to Switzerland for the purpose. DIGNITAS has members in 52 countries, of which United Kingdom membership (approximately 560 people) is second only to German. To join, members must pay a registration fee of 100 Swiss francs and a minimum annual subscription of 50 Swiss francs. Members may, in addition to supporting the aims of the organisation, apply for assistance with suicide for themselves. Since December 2004 DIGNITAS has levied a fee in such cases of 1000 Swiss francs to cover the preparations necessary for an assisted suicide and a further fee of 1000 francs for arranging burial, if the organisation is asked to do that.
203. A member who wishes for help with ending his or her life must request this in writing from DIGNITAS and send the organisation a copy of his or her medical records. These latter are considered by one of the doctors associated with DIGNITAS who, if he believes that the applicant's circumstances would enable him to write a prescription for lethal medication and on the understanding that he will be able at some point to assess him or her in person, agrees to the applicant being given a “provisional green light” (Q 2326). We were told by Mr Ludwig Minelli, Director General of DIGNITAS, that “about 80% of the members who have got the provisional green light never call again” but that, for those who persist with their requests, the organisation prefers that they come twice to Switzerland, once to see the physician and again to receive assistance with ending their lives. (Q 2326). He added, however, that in many cases—for example, where applicants were seriously ill or severely disabled—it was not possible to insist

on two visits and one visit, for confirmation of the Swiss doctor's assessment, was considered sufficient (Q 2326).

204. On arrival for the final or only visit, an applicant is met at the airport or railway station by a representative of DIGNITAS and taken to an apartment in Zurich which the organisation rents for the purpose. The DIGNITAS representative remains with the applicant throughout the visit, to ensure that his or her needs are met (including, if there has been no prior visit, a consultation with a doctor to confirm that the application meets the required criteria for assisted suicide), to oversee the necessary preparations (including the mixing of the lethal medication in a glass of water) and to make clear to the applicant that he or she is free at any time to discontinue the process. If the applicant wishes to go ahead, the medication is placed within his or her reach. When it has been ingested and death has occurred, the death is reported to the authorities. The DIGNITAS representative receives a fee for his or her services of 500 Swiss francs.
205. The Swiss Penal Code very clearly states that direct, active euthanasia is illegal. In practice this means that the final act has to be taken by the patient. According to Dr Zucco of EXIT, "we prepare the solution that the patient has to drink and we put it on the table and he or she is supposed to take it into his or her hands. This is the normal way" (Q 2413). However, there are cases where, because of a disability, the patient is unable to perform this action. In these situations the medication is intravenously infused. This means that the patient's final act is an extremely small part of the process—for example, in some cases "there is a small wheel that they have to push" (Q 2417). In the past some concern has been raised about these situations by the authorities. They felt that, as an infusion required more preparation, the patient might be less likely to decide not to proceed. However, according to Dr Zucco, "now it has been accepted because what we do is keep asking until the last second, 'Do you really want it?'. We try to make it easy for the patient to say no" (Q 2421). In these cases, Dr Hotz told us, the organisations are careful to make sure that they could not be accused of breaking the law: "we try in these cases to have two people, that the assistant from EXIT has a witness, and there have also been cases where a video has been made to prove afterwards that the person opened the valve, which is of course a delicate action" (Q 2419).
206. We found at DIGNITAS a similar trend to that at EXIT for making assistance with suicide more widely available. Mr Minelli told us that he would like to be able to help mentally ill people to commit suicide. "Until now," he said, "we have been very reluctant to have mentally ill people because there is one procedure in the Canton of Aargau where this question has been raised. We had last week a hearing at the court... If the decision is favourable, then I think we will have more possibilities to help mentally ill people" (Q 2371).
207. As indicated above, there are concerns in Switzerland about the activities of these organisations. Dr Christoph Rehmann-Sutter, President of the National Advisory Commission on Biomedical Ethics, referred to "the impossibility of the state having legal oversight of the practice of the organisations" (Q 2183). He felt that perhaps they "do not put enough weight on the lengthy process of evaluation and assessment of the person or on giving support to the person to make him or her change their mind" (Q 2183). Dr Brunner believed that the suicide organisations should be more

tightly regulated by the authorities. At present, he said, “there is no surveillance; they are associations without any state control. I think that should change” (Q 2290).

208. In Dr Brunner’s opinion a number of additional duties should be placed on the organisations to allow the authorities to regulate them more effectively. For example, while the organisations already publish annual reports of their activities, Dr Brunner felt that they should be legally required to disclose all their accounts as well, thereby making it easier for the authorities to satisfy themselves that no financial profit was being derived from assistance with suicide (a key consideration given the insistence of Swiss law on non-self-serving motives). He felt also that it was important to ensure that the organisations were staffed by “a good approved selection of people... because there is a danger from so-called angels of death” (Q 2263).

Belgium

209. The Belgian Act on Euthanasia was passed on 28 May 2002. It defines euthanasia as “intentionally terminating life by someone other than the person concerned at the latter’s request”⁶⁴. As such, it is similar to the Dutch definition and equates to what we have referred to in our report as voluntary euthanasia, though to avoid confusion in this section we use the Belgian terminology.
210. The Act differs from similar laws in Oregon, The Netherlands and Switzerland in that it legalises only euthanasia, not assistance with suicide. The conditions laid down include that the patient should have attained the age of majority, that the request should be “voluntary, well-considered and repeated” and that the patient should be “in a futile medical condition of constant and unbearable physical or mental suffering that cannot be alleviated”⁶⁵. The Act requires the assessing doctor to satisfy himself of, *inter alia*, “the durable nature” of the patient’s request for euthanasia. “To this end,” it prescribes, “the physician has several conversations with the patient spread out over a reasonable period of time”⁶⁶. The doctor must obtain a second medical opinion and, if the request satisfies all the criteria laid down, must “allow at least a month between the patient’s written request and the act of euthanasia”⁶⁷.
211. Acts of euthanasia must be reported to the authorities. The documentation for each case is reviewed by a Federal Control and Evaluation Commission (FCEC), which either confirms the physician’s immunity from prosecution (on the grounds that the paperwork submitted indicates compliance with the law) or refers the case to the public prosecutor.
212. The first report of the FCEC, covering the 15-month period from 23 September 2002 to 31 December 2003 recorded 259 cases of euthanasia, an average of 17 cases per month. More than 80% of these acts of euthanasia took place in Dutch-speaking Flanders (where some 60% of the population lives) and less than 20% in French-speaking Wallonia (where about 40% of the population lives). The 259 cases were reported by 143 different

⁶⁴ The Act, Section 2

⁶⁵ Section 3

⁶⁶ Section 3.2.2

⁶⁷ Section 3.3.2

physicians. In 2004, 347 cases of euthanasia were reported, an average of 29 cases per month. The Commission's first report did not report any instances of non-compliance with the law and did not see a need for new legislative initiatives.

213. The Act provides for patients requesting euthanasia to be made aware of the option of palliative care, though this is not seen as a filter—i.e. a process through which applicants must go in order to see to what extent their needs can be met through good quality palliative care before deciding to have their lives ended. Legislation on palliative care was introduced at the same time as the euthanasia law, though it is written in more general terms prescribing that every Belgian should have access to proper palliative care. According to the FCEC's first report, in 101 of the 259 reported cases of euthanasia (40%) in 2002/3 palliative care teams were consulted by attending physicians.

In Conclusion

214. We would like to record our sincere thanks both to the British Embassy staff in Seattle (for the visit to Oregon), The Hague and Berne who put considerable efforts into arranging visit programmes for us and briefing us on the demographic and cultural contexts of the countries we were visiting and to the organisations and individual witnesses in these places who took the time and trouble to meet us and to give oral evidence to support our inquiry.

CHAPTER 6: PUBLIC OPINION

Introduction

215. The question of whether assisted suicide and euthanasia should be legalised is a highly complex one, which is the principal reason why we were established as a select committee to explore the issues in depth with the appropriate professionals as a basis for reporting on Lord Joffe's Bill. But it is also a question which affects all of us as citizens, as we shall all die at some point and many of us will develop terminal illnesses or have the care of relatives in this situation. For this reason we have sought to form a view of how the public at large feel about a change in the law. In doing so we have not commissioned opinion research of our own but rather sought to measure, via a review of opinion surveys over the course of the last 10-20 years, the state of public opinion and any movements in it over that period. The report of the organisation (Market Research Services – MRS) which carried out the review for us appears as Appendix 7. This chapter summarises the findings. Necessarily we have been selective, focusing on those surveys which appear to have most immediate relevance to the Bill.
216. We also issued (see Appendix 2) a general invitation at the outset of our inquiry to anyone who wished to write to us, either by letter or by email, to express his or her personal views of the Bill. By 30 September 2004 we had received over 14,000 letters and emails in response, and some 83,000 cards or emails which formed part of organised petitions. After summarising the MRS report therefore we provide a synopsis of our mailbag.

General Caveats

217. MRS found that virtually all the surveys which had been carried out over the period were quantitative rather than qualitative in nature. That is to say, they consisted of opinion-poll type research directed at ascertaining how many respondents agreed or disagreed with specific propositions rather than in-depth research (on the focus group model) designed to assess responses as complex and sensitive issues are explored. For this reason, the report concluded, the surveys which have been carried out “tend to produce findings which at best may be considered one-dimensional. Simple, direct questions placed without a proper explanatory context and with limited options for reply can sometimes produce results which in fact may be misleading”⁶⁸. The same problem, says the report, applies to omnibus surveys, which are questionnaire surveys, such as the periodic British Social Attitudes (BSA) surveys, of nationally-representative samples of people covering a variety of topic areas. Such surveys “are particularly useful for simple issues such as consumer choices or social topics where respondents can be assumed to have a broad understanding of the topic area and of the consequences implied by particular response options. Where these conditions cannot be assumed and, as with euthanasia, the issues are potentially complex and far-reaching, the omnibus may not be the ideal tool for providing understanding. This seems to be particularly the case with surveys

⁶⁸ See Appendix 7, Section 2

of the general public, where an understanding of the potential impact of euthanasia/PAS legislation clearly cannot be assumed”⁶⁹.

Basic Attitude Surveys

218. These caveats having been made, the report concludes that, as regards basic public attitudes to assisted suicide and euthanasia, “it is evident that there is a great deal of sympathy, at least for the *concept* of euthanasia, and it seems likely that the level of sympathy has grown in recent years”⁷⁰. More specifically:
- A MORI poll of 1987 commissioned by two organisations active within the Pro-Life movement showed 72% support among those questioned for the legalisation of euthanasia;
 - BSA surveys in 1984, 1989 and 1994 showed an increasing majority (75% rising to 82%) in favour of doctors being allowed to end the life of a patient suffering from “a painful incurable disease”;
 - NOP polls commissioned by the VES in 1976, 1985, 1989 and 1993 showed a similar pattern of support for the proposition that adults should be allowed “to receive medical help to an immediate peaceful death if they suffer from an incurable physical illness that is intolerable to them”;
 - Similar NOP polls commissioned by the VES in 2002 and 2004 showed over 80% support for the proposition that “a person who is suffering unbearably from a terminal illness should be allowed by law to receive medical help to die, if that is what they want”.
219. The BSA survey, notes the MRS report, “differs from many others in at least one potentially important aspect—it is not commissioned by any outside organisation with a commitment to one side or other of the euthanasia debate”. MRS reports also the BSA’s conclusions that “the apparent trend towards the belief that euthanasia should be legalised in certain circumstances is part and parcel of a broad process of secularisation in western society—and, as such, seems set to grow” and that “neither of the ‘principled’ approaches of those for or against legalising euthanasia—liberty of the individual/duty of the state to preserve life—adequately represents the more pragmatic approach taken by most individuals when asked to view the issue on a case-by-case basis”⁷¹.

Surveys of Specific Groups or Aspects

220. The report proceeds to examine specific aspects of public attitudes to assisted suicide and euthanasia, as revealed in recent opinion surveys. Drawing on the 1994/5 BSA survey, MRS found little or no correlation between views on this subject on the one hand and age, gender, social class or party political allegiance on the other. It did however find some correlation between views of assisted suicide/euthanasia and certain personal characteristics, including:

⁶⁹ See Appendix 7, Section 2

⁷⁰ See Appendix 7, Section 3.1

⁷¹ See Appendix 7, Section 3.1

- Regular church attendance (more opponents)
 - Race (proponents mainly white)
 - United Kingdom nationality (more opposition in Scotland)
 - Able-bodied (more likely to oppose)
 - Education (proponents often more educationally qualified)
 - Links with other moral issues (opponents more likely to oppose abortion and—to some extent—capital punishment)
221. The attitudes of disabled people appeared to be more mixed. A 2003 poll for the Disability Rights Commission suggested, though on the basis of a small sample, that disabled people were concerned that they might be threatened by euthanasia legislation, while a 2004 YouGov survey carried out for the VES suggested that disabled people supported the ADTI Bill as strongly as able-bodied people.
222. A 2004 YouGov poll for the VES asked whether, if the law were to be changed to allow assisted suicide, respondents would trust their doctors more, less or the same. 70% said that that such a change in the law would not affect their trust in their doctors, while 9% would trust their doctors more and 9% less.
223. In an NOP omnibus survey, carried out in 2004 for the VES, 55% of respondents chose their doctor as the person whom they would wish to help them to die, if that were legal. The other choices were a relative (19%), a friend (9%) and—surprisingly low—a nurse (2%).
224. 60% of respondents in this last survey also felt that elderly people might be more nervous of going into hospital if euthanasia were to be legalised. Similarly, in the 1987 MORI poll referred to above 71% of respondents felt that people permanently dependent on others for medical or nursing care might request euthanasia in order not to be a burden on others, with only 12% disagreeing. The same survey, reported MRS, suggests that there is a fairly widespread disinclination to trust next of kin to request euthanasia for patients who are unable to communicate.
225. A 2004 VES-sponsored survey suggested that 47% of the population might be prepared to break the current law to assist someone else to take his or her own life in the case of terminal illness and unbearable suffering.

Views of Politicians

226. The views of politicians, as revealed in two surveys (1995 and 2004), are in striking contrast with those shown above. In 1995 70% of MPs opposed and 27% supported the principle of voluntary euthanasia for the terminally-ill. By 2004 the opposition had risen to 79%. MRS speculates that the gulf between the attitudes of politicians and those of the public might be explained by an assumption that “MPs, by definition, are more accustomed than most to taking into account the implications for society as a whole of proposed legal reforms as a separate issue to their personal feelings on the subject”⁷². Another reason might be a perception that, while a majority of the electorate as a whole might indeed favour or have no objection to a change in the law,

⁷² See Appendix 7, Section 4

the electoral consequences of favouring rather than opposing euthanasia could be more serious.

Views of Health Care Professionals

227. The MRS report then turns to the views of doctors, where a number of surveys have been carried out of varying quality and scope. The views expressed by doctors, the report observes, “generally enjoy a higher level of credibility on the assumption that medical practitioners can be assumed to have at least some direct experience of end-of-life conditions and therefore to be able to answer questions more meaningfully on this basis than others”⁷³.
228. According to the report, “euthanasia is clearly a subject which presents very many doctors with profound professional and personal dilemmas... It seems likely that medical professionals view the issue of the legalisation of euthanasia as less straightforward than the lay public as a whole because of their direct experience of working with patients, and there is some evidence to suggest that the closer the experience of end-of-life patients, the less sure the professionals are about the prospect of a change in the law in favour of euthanasia”⁷⁴.
229. Against this background MRS draws attention to:
 - a 1987 NOP telephone survey of 301 GPs, which suggested that, if the law were to be changed along the lines of the ADTI Bill, 53% would not carry out euthanasia on a patient, 35% would consider doing so and 10% might consider doing so.
 - a 1993 survey of 312 GPs and hospital consultants on attitudes of doctors to requests for euthanasia. 46% of those questioned (51% of GPs and 40% of consultants) would be prepared to consider practising euthanasia if asked by a competent patient. 32% would not. There was however a significant proportion of undecided respondents.
 - a 1995 Doctor magazine omnibus survey of 2150 doctors, in which 44% supported legal reform while 53% rejected it. 43%—slightly more GPs than hospital doctors—would consider practising euthanasia if it were legal.
 - a 1996 BMA News Review survey of 750 GPs, in which 46% of GPs supported and 44% rejected legal reform.
 - another 1996 survey, by Professor Sheila McLean, of 1000 respondents which showed, inter alia, a sharp distinction between the attitudes of medical practitioners towards assisted suicide on the one hand and euthanasia on the other—with 43% favouring the former and 19% the latter.
 - a 1998 postal survey of 322 United Kingdom psychiatrists, 38% of whom believed that euthanasia should be legalised and 35% of whom were willing to assess the psychological suitability of applicants for euthanasia.

⁷³ See Appendix 7, Section 5.1

⁷⁴ See Appendix 7, Section 5.1

- a 1999 survey of 333 geriatricians (45% of all United Kingdom doctors in this speciality), 80% of whom felt that euthanasia could never be justified, though 23% felt that it should be legal in some circumstances.
- a 2003 Opinion Research Business survey, carried out for Right to Life, which showed that, of 986 respondents, 22% would favour a change in the law to allow euthanasia, while 61% would be opposed.
- surveys (2003 and 2004) commissioned by the VES, which suggested that 33% of doctors might favour a change in the law, though with some indication of waning support for euthanasia between the two years.
- readership surveys by the Nursing Times in 1988 and 2003. In 1988 44% of nurses expressed a willingness to be involved in the administration of lethal drugs to suffering terminally ill patients, while in 2003 (according to the journal) two thirds of nurses believed that euthanasia should be legalised.
- 2004 qualitative research carried out by Help the Hospices, which concluded that the introduction of euthanasia legislation was seen within the hospice movement as capable of changing the ethos of hospice care for the worse and of eroding the relationship of trust between physicians, carers and patients.

The Committee's Own Postbag

230. Between 14 July, when the invitation to offer personal views to us was issued, and 30 September we received 9,709 letters and 2,720 emails from individuals who wished to comment on the ADTI Bill. In addition, there were 1,800 stereotyped letters, proformae or letters with multiple signatures. A large number of people also signed petitions either supporting or opposing the Bill.
231. Of the 12,429 people who wrote individual letters or emails to us, 6,284 (50.6%) supported the Bill and 6,145 opposed it. The balance of opinion is broadly the same if the stereotyped letters etc are included in the count—7,283 (51.2%) supporting and 6,946 (48.8%) opposing. Interestingly, letter-writers were more supportive of the Bill than email-senders—55.3% of them supported the Bill as against 33.6% of those who sent emails to us. Of those who sent in petitioning postcards or emails, 67,879 (including 57,765 cards addressed to the Human Rights Campaign and forwarded to the committee in bulk) favoured the Bill, while 15,374 opposed it

Conclusions

232. The MRS report drew the following conclusions on the results of the surveys which it had identified and analysed. It is worth quoting at length:
- “The research carried out up to this point into public and health sector attitudes to the legalisation of euthanasia is limited in value and cannot be accepted at face value as an authentic account of opinion within the United Kingdom. The subject matter is extremely complex and sensitive and therefore very challenging for anyone attempting to gain a meaningful understanding of opinion.
- “This is particularly the case with regard to the attitudes of the general public, whose real views on euthanasia are clearly obscured by a lack of

information on the subject and by the lack of opportunity to reflect in an informed way upon the implications of any change in the law for themselves and for society. The levels of agreement/disagreement with the concept of euthanasia which the numerous polls record are effectively built on what might be termed a “knee-jerk” reaction to the simple options provided by these polls and do not form a very useful guide to public opinion as support for legislative change.

“Nevertheless, the apparent groundswell in public agreement with the concept of euthanasia cannot be dismissed and it is evident that there is much sympathy at a personal level for the concept of legally releasing those wishing to die from their pain and those willing to help them from legal consequences. However, if the decisions of the Committee are to take authentic account of properly informed public opinion, a significant investment in more appropriate forms of research is undoubtedly required”⁷⁵.

233. On the results of surveys among health sector professionals, the report goes on to say that:

“health sector professionals tend by definition to be better informed about the context and potential implications of the legalisation of euthanasia, but here again most research is superficial in coverage and only a few attempts have been made to understand the basis of the opinions of doctors and others, which from the data appear to vary in different directions over time. Here too some fresh, impartial research, again of a deliberative nature, is required in order to gain a full and useful understanding of health sector views”⁷⁶.

⁷⁵ See Appendix 7, Section 6

⁷⁶ See Appendix 7, Section 6

CHAPTER 7: CONCLUSIONS

Introduction

234. In the preceding chapters we have attempted to summarise the evidence which we have received on the theory and practice of assisted suicide and voluntary euthanasia, on the experience of other countries which have introduced legislation in this area and on the current state of public opinion in Britain.
235. Our remit requires us to recommend whether Lord Joffe's Bill should proceed, with or without amendment, or not. It is clear to us that, with the likelihood of dissolution of Parliament in the near future, the Bill cannot be considered adequately in the present session due to shortage of Parliamentary time, and we therefore recognise that it cannot proceed. In these circumstances we consider that the appropriate course for us to take is to present a balanced account of the evidence which we have received; to recommend that an early opportunity should be sought for our report to be debated by the House; and to recommend also that, in the event that another bill dealing with this subject should be introduced into Parliament, it should, following a formal Second Reading, be sent to a Committee of the whole House for examination.
236. In order to assist in these deliberations we draw attention to a number of issues which have emerged in the course of our inquiry and which we would wish to see considered carefully by the House in any debate on our report or by a Committee of the House on any successor bill. Some of the issues which we shall raise in this chapter refer to matters raised in evidence during the course of our inquiry, while others have been prompted by consideration of specific aspects of Lord Joffe's Bill.

Covert Euthanasia

237. It has been suggested to us on a number of occasions that covert euthanasia already takes place both in this country and overseas and that the interests of patients and doctors would be better protected if this situation were to be recognised and legislation introduced to set out the precise limits of what is and is not acceptable. We have summarised the evidence which we have received on this subject in Paragraphs 76 to 79.
238. So far as we are aware, there has been no reporting of any of these alleged crimes and malpractices either to the police or to the appropriate medical regulatory body—the General Medical Council (GMC). It may perhaps be argued that those who have alleged malpractice can have had no ulterior motive for doing so. We do however feel that it would be unsafe for us to assume that there has been no exaggeration or misunderstanding in any of these surveys. The Sunday Times article, for example, to which we have referred in Paragraph 77 makes allegations about the administration of diamorphine which suggest that what is being referred to here is the so-called double-effect principle, whereby patients close to death can receive, within both the law and the GMC's guidelines of clinical practice, dosages of analgesics which are designed to relieve their pain or other distress, which could in certain circumstances have the effect of hastening their deaths but which are not administered with that intention. In his evidence to us Lord

Walton referred to “examples in the press of doctors saying that they have practised euthanasia”. Lord Walton considered that “the very great majority of them have been practising double effect and not euthanasia. I think this is something which has been widely misconstrued” (Q 2051).

239. While we are not able, for the reasons we have given, to accept as hard evidence the results of anonymous surveys or newspaper articles, this does not mean that we give no credence whatever to what they appear to be saying. Human experience shows that all laws are flouted to a greater or lesser extent, and we would be surprised if the law in this field were an exception. We recognise also the difficulties which medical practitioners may possibly feel about reporting malpractice on the part of colleagues, and this is certainly a factor to be taken into account. Bearing in mind however the trend towards death taking place in hospital rather than at home, the increasing prevalence of team-working in clinical care, the greater tendency for people to litigate where they suspect malpractice, and the potential for confusion with the legal administration of drugs to prevent restlessness and anxiety in the last hours of life, we would be surprised if covert euthanasia were being practised on anything like the scale which some of these surveys suggest.

A Question for Society as a Whole

240. We have recorded in Chapter One our view that, at the end of the day and when all the expert evidence has been heard, the acceptability or otherwise of a change in the law is a matter for society as a whole to decide through its legislators in Parliament. We feel it necessary however to add two riders to this view. First, we have summarised in Chapter Six the results of a general survey which we commissioned of public opinion research during the last 10-20 years. This survey certainly suggests that there is a substantial majority of the public at large who would support a change in the law. The authors do however caution that the opinion polls which have been carried out on this subject tend to be “simple, direct questions placed without a proper explanatory context”. It was also put to us by the BMA that such questions sometimes appear to suggest an either/or choice between intolerable suffering and an ending of a patient’s life, whereas the reality—for example, with good palliative care—was rather different (Q 303). Parliament must obviously weigh public opinion very carefully in an issue of this nature. But we suggest that, as with other deeply controversial issues (such as, for example, capital punishment or immigration), it must also assess to what extent opinion research based on answers to questions placed with little surrounding context represents a sound basis for changing the law.
241. Our second rider concerns the linkage between the general opinion of the public at large in this matter and the more specific views of professionals, such as doctors and nurses, who would be closely involved in the implementation of any change in the law. We are clear that Parliament’s assessment of the balance of good and harm arising out of any future bill must be sovereign and that, if Parliament should decide that the law should be changed, it would be for the various professionals, subject to exercise of any conscience clause, to carry out its provisions. Having said that, we are also conscious that, while some medical bodies (such as the Royal Colleges of Physicians and of General Practitioners) have adopted a neutral stance on the underlying principle (though not the provisions) of Lord Joffe’s Bill and while we have received evidence from some doctors who would favour a

change in the law, other medical bodies, including the British Medical Association and the Royal College of Nursing, have voiced opposition

242. It is in this context that the suggestion has been put to us by some of the witnesses whom we have heard that, if there should be a change in the law, its implementation should be placed outside the system of mainstream health care. We will not rehearse here the arguments for and against such an arrangement which have been put to us: they may be found in the accompanying volumes of our report—for example, in QQ 161, 324, 1123, 1196 and 2018—and they are summarised in Paragraphs 111 and 112 above. Here we would simply comment that assistance with the suicide of terminally ill people is not seen everywhere where it is practised as being necessarily an exclusive activity of the medical profession. Guidance issued by the Swiss Academy of Medical Sciences states that “assisted suicide is not part of a doctor’s task, because this contradicts the aims of medicine. On the other hand, consideration of the patient’s wishes is fundamental for the doctor–patient relationship”. The guidance also states that “helping someone to commit suicide is not a punishable offence when it is done for unselfish reasons. This applies to everyone”. As we have observed in Chapter Five, while a doctor’s prescription is required in Switzerland in order to obtain lethal medication, this requirement reflects the need to control dangerous drugs. And it might also be argued that, if society wishes to legalise acts which run counter to accepted medical ethics, it would be wise to consider whether such acts might not be carried out by other means.

Assisted Suicide and Voluntary Euthanasia

243. Lord Joffe’s Bill seeks to legalise not only medical assistance with suicide but also, in cases where self-administration of lethal medication is not possible, voluntary euthanasia. We have visited two places—Oregon and The Netherlands—which have gone down different roads in this regard and which show widely different death rates from this source. In Oregon less than 1 in 700 deaths is currently attributable to assisted suicide, whereas in The Netherlands the figure is more than 1 in 40, less than 10% of which are from assisted suicide while over 90% are as a result of voluntary euthanasia. If the Oregon experience were to be replicated here, we might expect, on the basis of a simple pro rata calculation, around 650 deaths a year from assisted suicide for the United Kingdom as a whole. The Dutch experience, on the other hand, could lead to around 13,000 deaths a year, of which some 12,000 would result from voluntary euthanasia. Given the qualifying conditions in Lord Joffe’s Bill, which are somewhat more restrictive than the Dutch Euthanasia Act, these latter figures probably overstate to some extent the numbers of likely deaths. And, as Lord Joffe proposed subsequently to tabling his Bill to restrict its geographical application to England and Wales only, the numbers (though not the proportions) would come down further. Nonetheless, the experience of other legislatures does suggest a strong linkage between the inclusion of voluntary euthanasia in assisted dying law and a significantly higher rate of take-up.
244. There was general agreement among our witnesses that the number of people who might be regarded as serious about ending their lives, who are not psychiatrically ill and who are unlikely to be deflected from their purpose is very small indeed and comprises to a large extent terminally ill people who have strong personalities and a history of being in control of their lives and whose suffering derives more from the fact of their terminal illness and from

the loss of control which this involves than from the symptoms of their disease. If therefore it should be accepted by the House that there is a case for such exceptional individuals to be afforded assistance to end their lives, consideration would need to be given to how the parameters of any new law could be set in such a way as to ensure that the take-up rate is limited to such people. In this context we cannot but observe an apparent link between the scope of assisted dying legislation in other countries and the incidence of deaths from this source in those places. The much smaller numbers of deaths in countries where only assisted suicide is legal suggests strongly that such a restriction, with its emphasis on the individual taking responsibility for the final stage of ending his or her life, has the effect of making those who are minded to end their lives think very carefully before taking action to give effect to their wishes.

245. There are however other reasons why it might be considered that there is a case for any new bill to be narrower in scope than the present one. From the evidence we have received it is clear that, while there are indeed some doctors who support a change in the law, the medical profession as a whole is at best ambivalent on the subject and in many cases opposed. On the other hand, it appears that there would be rather less unhappiness about a law which is limited in its scope to assisted suicide. Dr Wilks referred to “an impression... that still a minority of doctors, but a larger number, would support a change in the law on physician-assisted suicide than would support a law on euthanasia”. There was, he believed, “a feeling of comfort that there is a partnership involved between the doctor and the patient as opposed to the doctor being the agent”(Q 293). This endorses what we were told in Oregon—that any proposal to extend the ODDA into the field of euthanasia would encounter much greater opposition from the medical profession (Q 1048). It must also be the case that any blurring of the line between voluntary and involuntary assisted dying is likely to occur more easily with voluntary euthanasia than with assisted suicide.
246. We therefore recommend that, if a successor bill should be introduced for consideration by Parliament, it should distinguish clearly between assisted suicide and voluntary euthanasia and thereby give the House the opportunity to address these two courses of action separately, as the considerations involved in each are very different. It would of course be necessary to take into account the situation of a small minority of terminally ill people, such as some with MND, who may be unable to administer to themselves prescribed lethal medication. According to Professor Timothy Quill of the University of Rochester, New York, this need not mean that no help can be given to patients in this position (Q 2123). And it was also pointed out to us by witnesses in Switzerland (QQ 2413-2421) that there are means by which physically incapacitated people can be enabled to administer lethal medication to themselves if they are determined to do so. The key issue however in our view is that responsibility for the ultimate act rests with the patient.

The Implementation of Assisted Suicide or Voluntary Euthanasia

247. In his evidence to us Lord Joffe made clear that the primary aim of his Bill was to legalise assisted suicide and that, while it did provide also for voluntary euthanasia, this latter course would be authorised only where the patient was physically incapable of taking his or her own life with the medication supplied (Clause 1(2) and Q 70). Yet those clauses of his Bill

(Clauses 5 and 7) which deal with the duties of the physician after an applicant has passed all the prescribed tests and made a written declaration that he or she wishes to die are unspecific about the actions which have to be taken by the doctor: they speak simply of the doctor “assisting the patient to die”. This is in contrast to the detail which is included in those clauses of the Bill which are concerned with the making and assessing of applications and in those which deal with the paperwork following the patient’s death.

248. We therefore recommend that, should another bill be introduced into Parliament with the aim of legalising assisted suicide or voluntary euthanasia, it should spell out what a doctor may and may not do in circumstances where an applicant has met all the specified criteria and made a formal declaration. In the case of a provision seeking to legalise assisted suicide only, we would expect, for example, to see set out the procedures under which a prescription for lethal medication may be given and the necessary drugs obtained, along with the responsibilities, rights and immunities of the persons involved, such as doctors and pharmacists. In the case of a provision which sought to legalise also voluntary euthanasia, we would expect to see set out a detailed procedure for establishing whether a request fell within tightly-defined criteria for voluntary euthanasia rather than assisted suicide and, in the event that it did, for putting the necessary action into effect.

Qualifying Conditions

249. Having addressed the scope of any future bill on this subject, it is necessary to consider the qualifying conditions for whatever it is proposed to legalise. Lord Joffe’s Bill contains three key conditions—terminal illness, competence and unbearable suffering. In Chapter Four we have summarised the evidence which we have received on each of these conditions. Here we record some general conclusions.
250. The root of the problem over linking assisted suicide or voluntary euthanasia with terminal illness lies in finding a formula for defining terminal illness in such a way as to ensure an appropriate degree of accuracy in diagnosing and forecasting the course of a patient’s disease. Otherwise there is a risk that people who believe that they have a short time to live (or indeed that they are terminally ill at all) might be encouraged to end their lives on the basis of inaccurate prognoses or diagnoses. There is however clearly a difference between the popular view of terminal illness, which employs phrases like “three months to live”, and the reality of clinical practice, in which prognosis is far from being an exact science and in which there can be wide variations from an overall norm.
251. We recommend therefore that, if another bill along the lines of Lord Joffe’s should be introduced into Parliament, consideration should be given to a definition of terminal illness which is based on the realities of clinical practice and is sufficiently precise in terms of the exception to the general law which it is proposing in order to ensure proper protection for those who may make use of it.
252. The mental competence of an applicant for assisted suicide or voluntary euthanasia is a crucial condition. Lord Joffe’s Bill defines competence as “having the capacity to make an informed decision”. We would suggest however that any definition of competence needs to include two dimensions—that an applicant must be capable of understanding his or her situation and of reaching a reasoned decision without external pressure; and

that it must be clear that an applicant's judgement is not temporarily clouded by psychological impairment which, as is frequently the case in people who are terminally ill, may be transient and treatable. We are reasonably comfortable with the thought that an assessing doctor should be able to spot cases where an applicant is *non compos mentis*, but we are less clear that cases of treatable depression or external pressure will be so readily apparent. The present Bill requires a psychiatric assessment only in cases where either of the two doctors involved has reason to believe that an applicant may not be competent. We have therefore considered whether given the importance of this condition being met such an assessment should not be mandatory in all cases.

253. In doing so we have asked ourselves whether there is not, perhaps, an element of unwitting condescension in saying to someone who is suffering unbearably and has asked to have his or her life ended that he or she ought to be seen and assessed by a psychiatrist. Some might argue that depression is an occupational hazard of living for all of us and that we all take decisions at different stages of our life which may well be coloured, to a greater or lesser extent, by depression. Yet no one suggests to us psychiatric involvement. However, while it seems to us that this is a fair point to make in relation to life generally, we believe that the situation of someone who is seeking medical assistance with suicide or voluntary euthanasia is unique in that the act involved is one of the utmost gravity and, if implemented, irreversible. Society already makes strenuous efforts to frustrate attempted suicides on the basis that the person who has attempted to take his or her may well think better of it at a later date, and we have been told by a number of those who gave evidence to us that people who ask for assistance to die frequently change their minds either because they have received better palliative care or simply because they have re-assessed and come to terms with their situation.
254. We therefore recommend that in the framing of any future bill consideration should be given to the inclusion of a requirement for any applicant for assistance with suicide or voluntary euthanasia to be given a psychiatric assessment in order both to confirm that the request is based on a reasoned decision and is free from external pressure and that the applicant is not suffering from a psychiatric or psychological disorder causing impaired judgement. In cases where such disorder was apparent, we would expect an applicant to be offered treatment. If a way could be found of confidently limiting applications to strong-minded individuals who are clear about what they want, such a requirement would be of less importance. Otherwise it would be necessary to weigh the inconvenience which a psychiatric assessment might cause to determined applicants against the need to protect less resolute persons from decisions arising from psychiatric disorder or external pressure.
255. Lord Joffe's Bill includes the condition that an applicant must be suffering unbearably. This is undoubtedly the most difficult of the qualifying conditions to define. We are clear that there must be a filtering role for physicians who assess applications for assisted suicide or voluntary euthanasia in order to weed out situations which no reasonable person would regard as grounds for such action. We recognise however the very real difficulty which doctors might face in declining to accede to requests based on patients' subjective assessments of their own suffering or in satisfying themselves that such suffering derives from the presence of a terminal illness. It has also been suggested by some of our witnesses that there is an element

of illogicality in allowing assisted suicide or voluntary euthanasia for patients whose medical state is such that they are likely to secure early release from their unbearable suffering by natural means while refusing it to others with chronic conditions whose suffering is likely to be more prolonged—or indeed to people, such as prisoners serving life sentences, who have no serious medical condition at all but who may nonetheless be suffering unbearably.

256. An option which occurs to us is to make “unrelievable” or “intractable” rather than “unbearable” suffering or distress a condition of any future Bill. Such a definition would enable a more objective medical assessment to be made of a patient’s suffering and should ensure that all available steps were taken to relieve distress before an application for assisted suicide or voluntary euthanasia could move forward. Consideration would need to be given to the position of individuals whose suffering was existential—i.e. deriving from feelings of loss of control or of self-worth—rather than a result of the symptoms of their terminal illness. This is the group of people, to whom we have drawn attention earlier in our report, who appear to have the most settled wish for their lives to be ended. A test of “unrelievable” suffering might ensure that an application would not be taken at face value but that action would be taken to attempt to relieve any suffering and that only in those cases where this was unsuccessful would assisted suicide or voluntary euthanasia be considered further. We recommend therefore that consideration should be given in any future bill to including a test of “unrelievable” or “intractable” in place of “unbearable” distress.

Palliative Care

257. The current Bill seeks to make the provision of palliative care complementary to the opportunity to have assistance with suicide or voluntary euthanasia. It prescribes that “the attending physician shall ensure that a specialist in palliative care has attended the patient to discuss the option of palliative care” (Clause 3(1)). A number of our witnesses have described this as an unrealistic provision. We were told that “this requirement does not reflect the reality of specialist palliative care practice. Palliative care depends on continuity and relationship. It would not be possible to undertake a full and proper assessment of a patient’s full palliative care needs in the time allowed for a short consultation”⁷⁷. Expanding on this, Ms Vicky Robinson, a Nurse Consultant in palliative care at St Christopher’s Hospice, asked whether the real purpose of Clause 3(1) of the Bill “is to complete a requirement for the process of attaining assisted dying or to assess how a person’s suffering may be supported, and if possible relieved, through palliative care. If it is the former, it is not a palliative care assessment. If it is the latter, then assessment takes, at the very least, a week and, in proportion to the severity of the suffering experienced, may take months” (Q 354). Of course, the Bill does not prescribe an “assessment”, but rather a discussion of “the option of palliative care”.
258. Lord Joffe suggested to us that for terminally ill people palliative care should be the first option and that assisted suicide or voluntary euthanasia should be considered only as a last resort (Q 70). We would support this view in the event that there were to be a change in the law. The problem is that not every terminally ill patient who is suffering will have access to good quality

⁷⁷ See Volume II: Evidence, HL Paper 86-II, Page 135

symptom control. In the words of Help the Hospices, “experience of pain control is radically different from the promise of pain control, and cessation is almost unimaginable if symptom control has been poor. On this view patients seeking assistance to die without having experienced good symptom control could not be deemed fully informed”⁷⁸. Clearly therefore something more than a simple consultation with a palliative care doctor or nurse is needed if patients contemplating assisted suicide or voluntary euthanasia are to be able to make fully informed choices. The difficulty lies in the somewhat patchy availability of good quality palliative care. If however a future bill is to be able to claim with credibility that it is offering assistance with suicide or voluntary euthanasia as complementary rather than as an alternative to palliative care, it may need to find a way of resolving this dilemma.

Waiting Period

259. The present Bill prescribes that a minimum a 14 days shall elapse between “the date on which the patient first informed the attending physician” of his or her wish for assisted suicide or euthanasia and the date on which one of these actions is taken (Clause 2(1)). Lord Joffe explained to us that the reason for starting the clock, so to speak, at the time of the request rather than at the signing of the declaration was concern “that, if there were so many steps (and we have already included a surprising number of safeguards), the patients will all have died before we get through them”(Q 70). Others expressed different concerns. The NCHSPCS considered that “it is possible that the period leading up to the signing of the declaration will become focused heavily on process, as the patient and his professional carers seek to ensure that the Bill’s requirements have been complied with. Consideration should be given to whether there should be a waiting period after the declaration period has been signed, which would enable the patient to focus not on the process of qualifying for and making a declaration but on the decision whether then to proceed”⁷⁹.
260. There is, of course, nothing to prevent an applicant doing just that under the present Bill. Once a declaration is signed, the applicant would be under no obligation to proceed with assisted suicide or euthanasia either at once or indeed at all. But there is, we feel, some force in the NCHSPCS’s argument that, in the patient’s own best interests, he or she should be prevented by law from acting without reflection—or even from feeling subconsciously that, having proceeded as far as the signing of a declaration and having put a number of people to a lot of trouble, he or she should not draw back. In the case of a bill seeking to legalise assisted suicide only, the need for a “cooling-off” period would seem less important, as the evidence we received in Oregon suggested that many of those who receive lethal prescriptions do not immediately ingest them but rather keep them as a form of insurance policy. In the case of voluntary euthanasia, however, consideration should be given to a pause before a patient makes his or her final decision on an irrevocable course of action. The length of such a pause would need to balance the need to avoid increased suffering for determined individuals against the desirability of providing time for reflection for the less resolute.

⁷⁸ See Volume II: Evidence, HL Paper 86-II, Page 702

⁷⁹ See Volume II: Evidence, HL Paper 86-II, Page 133

Responsibilities of Physicians

261. We have already addressed (Paragraphs 247 to 248) the important need for explicit wording in any future bill to define precisely the actions which a doctor may or may not take after a patient has signed a declaration and requested assisted suicide or euthanasia. But it is necessary also to consider the position of doctors who have conscientious objections to assisted suicide or voluntary euthanasia. Clause 7 of the present Bill seeks to deal with this issue, providing as it does that “no person shall be under any duty... to participate in any diagnosis, treatment or other action... to which he has a conscientious objection” (Clause 7(1)) and that, if either an attending or consulting physician has such an objection when confronted with a patient who is seeking his services under the Bill, “he shall take appropriate steps to ensure that the patient is referred without delay” to an attending or consulting physician “who does not have such a conscientious objection” (Clause 7(2)(3)). We have already pointed out (Paragraph 32) that, in the light of concerns expressed by the Joint Committee on Human Rights⁸⁰ that Clauses 7(1) and 7(2) “give rise to a significant risk of violation of Article 9(1) of the ECHR”, Lord Joffe has proposed to amend this section of his Bill in such a way as to remove the obligation on physicians with a conscientious objection to refer patients in the way proposed. We recommend that such an amendment should be reflected in any successor bill.
262. Conscientious objections could however arise not only from doctors but also from other health care professionals, including nurses and pharmacists. The present Bill however is rather narrowly drawn on this point. We suggest therefore that any new bill should reflect, in addition to the revision of Clause 7 which Lord Joffe has proposed for his own Bill, the need to protect the interests of all members of the clinical team. In particular, it should seek to address such situations as that in which, for example, a nurse with conscientious objections is asked by a patient to raise with a doctor on his or her behalf a request for assisted suicide or voluntary euthanasia.
263. It has also been drawn to our attention that care of the terminally ill is often carried out by multidisciplinary teams and that a number of doctors, nurses and other health care professionals could be involved, and might feel themselves implicated, in any action taken under the terms of the Bill to respond to a request for assisted suicide or euthanasia. Dr Vivienne Nathanson, for the BMA, told us that in many cases, such as, for example, in spinal injury cases, “you are not talking about one doctor, you are talking about teams of doctors, and I think there would be great difficulty in deciding who was, if you like, the primary care doctor and decision-maker, because the nature of these teams is that they work as equals” (Q 299). The GMC told us that its own guidance indicates that it should be clear at any one time who has responsibility for patient care (Q 339). It added that, while in theory this issue did not present insurmountable obstacles, the practical implications could be more complex (Q 340). Any new bill would therefore need to be drafted in such a way as to cater satisfactorily for such situations—for example, if the doctor with primary responsibility for a terminally ill patient wished to respond to a request for assisted suicide or voluntary

⁸⁰ HL Paper 93 Paragraph 3.16

euthanasia, where would that leave other members of the team who had conscientious objections?

Pain Relief

264. The present Bill provides (Clause 15) that “a patient suffering from a terminal illness shall be entitled to request and receive such medication as may be necessary to keep him free as far as possible from pain and distress”. This clause has attracted a good deal of criticism from witnesses. Lord Joffe told us that there were two reasons for its insertion into his Bill—that there was evidence that many patients do not get sufficient pain relief and that some doctors are reluctant to give increased doses of pain relief because of fear of prosecution (Q 70). He added that “it is only where a patient is suffering and either the GP or the hospital are not providing sufficient and adequate medication to control the pain that they would seek to invoke this right” (Q 157).
265. The NCHSPCS commented that “the administration of pain relief is well-established in clinical practice and need have no bearing on or connection to PAD [physician-assisted dying]. It is unprecedented that a therapeutic course of action requires an act of legislation”⁸¹. Echoing this view, the BMA said that Section 15 of the Bill was “unnecessary and plays on public fears about the possibility of intolerable or unrelieved pain at the end of life”⁸².
266. There is also, it seems to us, a practical objection to what is being proposed here. In the event that a patient should exercise his or her right under this section, on what basis would he or she argue that the pain relief made available was insufficient? And on what basis would he or she demand the correct drugs or dosage? If it is envisaged that the basis of a claim under Clause 15 would be the patient’s own perception of his or her pain, that would appear to be tantamount to authorising a patient to override the clinician’s judgement. We cannot judge whether some doctors are currently acting in a niggardly manner with regard to pain relief, though the allegation does not sit easily alongside others which have been made (see Chapter Four) that many doctors are over-using pain relief. In fact, Lord Joffe has proposed to withdraw Clause 15 from his Bill, and we recommend that, if there should be a new bill seeking to legalise assisted suicide or voluntary euthanasia, it should not seek also to regulate pain relief.

In Conclusion

267. The above are the principal concerns which have emerged in our inquiry both generally and in regard to the current Bill. A number of lesser, though nonetheless important, issues have also been raised, including the role of witnesses to declarations by patients, the provision of immunity from legal action to physicians and others who take action under the terms of the Bill and the role of the proposed monitoring commission. We do not rehearse them here because the Bill as it stands cannot proceed due to shortage of time.
268. There have been differences of opinion among members of the committee on the relative importance of issues and on the interpretation of the evidence we

⁸¹ See Volume II: Evidence, HL Paper 86-II, Page 133

⁸² See Volume II: Evidence, HL Paper 86-II, Page 111

have been given. In these circumstances we have agreed that the most appropriate way to proceed is to summarise, in as balanced a manner as possible, the evidence we have received on both the principles underlying the Bill and the practical implications which such legislation would have and to draw the attention of the House to a number of key issues arising from this which seem to us to be pertinent to the consideration of any future bill which might be brought forward on this subject. With this in mind we now submit our report.

Recommendations

269. We recommend that:

- (a) an early opportunity should be taken for our report to be debated by the House in the next session of Parliament (Paragraph 235).
- (b) in the event that another bill of this nature should be introduced into Parliament, it should, following a formal Second Reading, be sent to a Committee of the whole House for examination (Paragraph 235).
- (c) any such bill should take account of the following considerations which have emerged in the course of our inquiry:
 - (i) a clear distinction should be drawn in any future bill between assisted suicide and voluntary euthanasia in order to provide the House with an opportunity to consider carefully these two courses of action, and the different considerations which apply to them, and to reach a view on whether, if such a bill is to proceed, it should be limited to the one or the other or both (Paragraphs 243-246);
 - (ii) any future bill should set out clearly the actions which a doctor may and may not take either in providing assistance with suicide or in administering voluntary euthanasia (Paragraphs 247-248);
 - (iii) if a future bill should include terminal illness as a qualifying condition, this should be defined in such a way as to reflect the realities of clinical practice as regards accurate prognosis (Paragraphs 250-251);
 - (iv) a definition of mental competence in any future bill should take into account the need to identify applicants suffering from psychological or psychiatric disorder as well as a need for mental capacity (Paragraphs 252-254);
 - (v) consideration should be given in any future bill to including “unrelievable” or “intractable” suffering or distress rather than “unbearable” suffering as a criterion (Paragraphs 255-256);
 - (vi) if a future bill is to claim with credibility that it is offering assistance with suicide or voluntary euthanasia as complementary rather than alternative to palliative care, it should consider how patients seeking to end their lives might experience such care before taking a final decision (Paragraphs 257-258);
 - (vii) in setting a waiting period between an application for assisted suicide or voluntary euthanasia and the carrying out of such

actions, any future bill should seek to balance the need to avoid increased suffering for determined applicants against the desirability of providing time for reflection for the less resolute. Such a waiting period is of less importance in the case of assisted suicide but needs to be considered carefully in the case of voluntary euthanasia (Paragraphs 259-260);

- (viii) any new bill should not place on a physician with conscientious objection the duty to refer an applicant for assisted suicide or voluntary euthanasia to another physician without such objection; it should provide adequate protection for all health care professionals who may be involved in any way in such an application; and it should ensure that the position of persons working in multi-disciplinary teams is adequately protected (Paragraphs 261-263);
- (ix) any new bill should not include provisions to govern the administration of pain relief by doctors (Paragraphs 264-266).

APPENDIX 1: SELECT COMMITTEE ON THE ASSISTED DYING FOR THE TERMINALLY ILL BILL

Extract from the House of Lords Minute 29 November 2004

Assisted Dying for the Terminally Ill Bill [HL]— It was moved by the Lord Joffe that the bill be now read a second time; the motion was agreed to and the bill was committed to a Select Committee.

Extract from the House of Lords Minute 30 November 2004

Assisted Dying for the Terminally Ill Bill [HL]—It was moved by the Chairman of Committees that, as proposed by the Committee of Selection, the following Lords be named of the Select Committee on the bill:

The Earl of Arran
 The Lord Carlile of Berriew
 The Baroness Finlay of Llandaff
 The Rt Hon Baroness Hayman
 The Rt Hon Baroness Jay of Paddington
 The Lord Joffe
 The Rt Hon Lord Mackay of Clashfern
 Professor Lord McColl of Dulwich
 The Lord Patel
 The Rt Rev Lord Bishop of St Albans
 The Lord Taverne
 The Baroness Thomas of Walliswood
 The Lord Turnberg

That the Committee have power to appoint specialist advisers;

That the Committee have power to adjourn from place to place;

That the minutes of evidence taken before the Committee from time to time shall, if the Committee think fit, be printed;

That the proceedings of the Committee on the Assisted Dying for the Terminally Ill Bill [HL] in the last session of Parliament be referred to the Committee; and

That the Committee do meet on Thursday 2nd December;

The motion was agreed to.

Declaration of Interests

ARRAN, Earl of

Remunerated directorships

Autotag (Production of Tags for motor vehicles)

Landholdings

Approx. 1 acre of allotment holdings in High Roding (Essex)

Approx. 65 acres near Kings Langley (Herts)

Office-holder in voluntary organisations

Chairman, Children's Country Holidays Fund

*Trusteeships**Trustee of certain family trusts**Voluntary organisations**Chelsea Physic Garden***CARLILE OF BERRIEW, Lord***Non-parliamentary consultant**Adviser to Mr. R. Hobson (in connection with his business and family interests) (7 April 2004)**Remunerated directorships**Director, 4-5 Bell Yard Limited (holding company of lease to part of the barristers chambers of which a member)**Non-Executive Director, Wynnstay Group plc (agricultural feed manufacturers, merchants of agricultural and country goods, fuel oil distributors)**Regular remunerated employment**Deputy High Court Judge**Independent Reviewer of terrorism legislation**Practising barrister (Queen's Counsel) (Head of Chambers, 9-12 Bell Yard)**Recorder**Fellow of King's College, London**Trusteeships of cultural bodies**Chair of Trustees of Oriel 31 (art gallery in Newtown, Powys)**Non-executive Director of Mid Wales Opera**Office-holder in voluntary organisations**Member of Council, JUSTICE**Royal Medical Foundation of Epsom College (Member of Council)**Trustee, Nuffield Trust**Trustee, White Ensign Association (charity for Royal Navy serving and former personnel)**Vice Chair and Trustee, REKINDLE (a mental health charity)***FINLAY OF LLANDAFF, Baroness***Non-parliamentary consultant**Employed as a clinician by Marie Curie Cancer Care (no parliamentary or political consultancy given)**Regular remunerated employment**Professor of Palliative Medicine and Vice Dean, University of Wales College of Medicine**Clinical Consultant, Marie Curie Cancer Care**Clinical Consultant, Velindre NHS Trust**Membership of public bodies**Governing Body, Howell's School Llandaff GDST**Patron, Fundraising Appeal, Church in Wales Primary School, Llandaff**President, Association of Chartered Physiotherapy**Member, Stakeholder Advisory Commission for First Great Western Trains**Office-holder in voluntary organisations**Founder Member, Scientific Committee, Cancer Research UK**Member, International Scientific Expert Panel, Cicely Saunders Foundation**President, Multiple Sclerosis Cymru**Voluntary organisations**Vice Patron, Purley Park Trust's New Building Project Appeal**Patron, New Bristol Symphonia Orchestra*

Vice Patron, Appeal for the Memorial to Women of World War II
Director, Institute of Medical Ethics
Patron, Westminster Diet and Health Forum (9 December 2003)

HAYMAN, Baroness

Trusteeships of cultural bodies
Member of the Board of Trustees, Royal Botanic Gardens, Kew, Surrey
Director of Enterprises, Royal Botanic Gardens, Kew (unpaid) (18 May 2004)
Office-holder in pressure groups or trade unions
Chairman, Specialised Health Care Alliance (unpaid) (18 May 2004)
Office-holder in voluntary organisations
Chairman, Cancer Research UK
Member of the Board of RoadSafe

JAY OF PADDINGTON, Baroness

Remunerated directorships
Non-executive Director, BT plc
Non-executive Director, Independent News and Media plc
Member, International News and Media International Advisory Board
Landholdings
Second holiday home in Co. Cork, Eire regularly let for periods of up to 2 months each year
Trusteeships of cultural bodies
Member of the Board of the Institute of Contemporary British History (from October 2001)
Member of the ITV Television Trust
Office-holder in voluntary organisations
Chair of the Overseas Development Institute

JOFFE, Lord

Office-holder in voluntary organisations
Chair, The Giving Campaign
Chair, Management Accounting for Non-Government Organisations (MANGO)
Trustee, The Smith Institute
Trustee, The Legal Assistance Trust
Trustee, The Canon Collins Educational Trust for Southern Africa
Trusteeships
Trustee, J G & V L Joffe Charitable Trust
Trustee, Sumner Wilson Charitable Trust
Voluntary organisations
Member, Voluntary Euthanasia Society

McCOLL OF DULWICH, Lord

Remunerated directorships
The Wolfson Foundation
Collingham Sixth Form College
Regular remunerated employment
Professor working in the Department of Anatomy of King's College at the Guy's Hospital campus
Membership of public bodies

Fellow of King's College, London
Member of the Court of Patrons of the Royal College of Surgeons of England
Governor of St Paul's School
Chairman of the Board of Governors of James Allen's Girls' School
Office-holder in voluntary organisations
Chairman of Mercy Ships UK (a charity)
Chairman of Tommy's Campaign Medical Advisory Group
Member of the Advisory Board of the Shaftesbury Society
Member of the Board of Advisers of the Centre for Bioethics and Public Policy
President of Limbless Association
President of the Royal Medical Foundation of Epsom College
President of The Leprosy Mission
Vice Chairman of Mercy Ships International
Vice President of Disability Partnership
Vice President of Disabled Living Foundation
Vice President of John Grooms Association
Vice President of the British Digestive Disorders Foundation
Vice President of the Mildmay Hospital in Hackney (the first hospice for people dying of Aids in Europe) and a similar centre in Uganda

MACKAY OF CLASHFERN, Lord

Regular remunerated employment
General Editor of Halsbury's Laws of England
Landholdings
Own approximately 90 acres of growing trees at Canban, Invernesshire
Membership of public bodies
Chancellor of Heriot-Watt University
Office-holder in voluntary organisations
Patron of Lawyers' Christian Fellowship
Vice President, The Princess Royal's Trust for Carers
Honorary President, Scottish Bible Society
Honorary President, St. Andrew's Preservation Trust
Trusteeships
Trustee of Faculty of Advocates' Charitable Trust
Trustee of George Heriot's Bursary Appeal Trust
Trustee of the Scottish Inheritance Fund
Voluntary organisations
Membership of Cancer UK

PATEL, Lord

Regular remunerated employment
Chairman, NHS Quality Improvement, Scotland
Secretarial research and assistance
Secretarial assistance on part-time basis from NHS Quality Improvement
Membership of public bodies
Chairman, NHS Quality Improvement, Scotland
Member, Armed Forces Pay Review Board
Member, Foundation of Dundee High School
Vice President, International Federation of Obstetrics and Gynaecology
Office-holder in voluntary organisations
Trustee, White Top Foundation (charity)
Council Member, The STROKE Association (charity)
Patron, South Asia Health Foundation (charity)

ST ALBANS, Lord Bishop of

Regular remunerated employment
In receipt of episcopal stipend
Office-holder in voluntary organisations
Assistant, Corporation of the Sons of the Clergy
Chairman, Church of England Hospital Chaplaincies Council
Chairman, East of England Churches Network
Director, Herts and Beds Shared Churches Ltd
Director, Hockerill Education Trust
Director, St Albans Cathedral and Abbey campaign
Director, St Albans Diocesan Board of Finance
President, Haileybury School
President, St Albans Bach Choir
Trustee, Tantur Association (UK)
Vice President, Clergy Orphan Corporation
Vice President, Lampeter Alumini
Vice President, National Benevolent Fund for the Aged
Chairman, Council of Christians and Jews
Chairman, Member of panel of chairman of the General Synod
Voluntary organisations
Member, Action Aid
Member, Churches Committee for Hospital Chaplaincy
Member, Old Monmothian Club
Member, Royal Society of Arts
Patron, Abbeyfield Society
Patron, Isabel Hospice, Welwyn Garden City and numerous other
Hertfordshire and Bedfordshire voluntary organisations

TAVERNE, Lord

Regular remunerated employment
Chairman, Monitoring Board, Axa Sun Life plc
Non Executive Chairman, IFG Development Initiatives Ltd
Office-holder in voluntary organisations
Chairman of Sense About Science
Chairman of Trustees, Alcohol and Drug Addiction Prevention and
Treatment (ADAPT) Ltd
Chairman of Trustees, Iran Aid Foundation
Trustee, The Health and Science Communication Trust

THOMAS OF WALLISWOOD, Baroness

Visits
Visit to Calais (March 2002) to study railfreight/immigration and asylum
problems (1 day)
Visit to Madrid (October 2002) under the auspices of the Euro-Med
Women's Conference
Visit to Madrid (10-11 June 2003) with All-Party Group on Population,
Development and Reproductive Health

TURNBERG, Lord

Non-parliamentary consultant

Member, Clinical Advisory Board of Nations Healthcare

Chair, Clinical Advisory Board of Inventures

Member, Bio-ethics Advisory Committee of Astra Zeneca

Remunerated directorships

President, Medical Protection Society

Regular remunerated employment

Scientific Adviser, Association of Medical Research Charities

Office-holder in voluntary organisations

Chair, Board of Health Quality Service

Trustee, Wolfson Foundation

Vice President, Academy of Medical Sciences

APPENDIX 2: CALL FOR EVIDENCE DATED 14 JULY 2004

A House of Lords Select Committee has been appointed to consider and report on the Assisted Dying for the Terminally Ill Bill. The Members of the Committee are shown at Appendix 1. The purpose of this letter is to invite organisations with a known or presumed interest in the Bill to submit written evidence to the Committee. Submissions should follow the guidance given below and should reach the Committee as soon as possible, and in any case not later than Friday 3 September 2004.

A copy of the Bill may be found at Annex 2. The full text of the Bill is also available on the internet at:

<http://pubs1.tso.parliament.uk/pa/ld200304/ldbills/017/2004017.htm>

or from The Stationery Office: tel. 08457 023474. The reference is HL Bill 17, Session 2003-04.

The Bill is a Private Member's Bill, which was introduced into the House earlier this year and had its Second Reading on 10 March 2004. Its main purpose is to enable, in specified circumstances, a terminally ill competent adult to request medical assistance to die.

The Select Committee's terms of reference are the Bill itself. When the Committee produces its report, it will be expected to recommend whether the Bill should proceed and, if so, whether or not in an amended form (The Committee has the power to amend the Bill).

Those wishing to submit written evidence should follow the guidance given below:

Written evidence should be submitted to the Committee no later than Friday 3 September 2004.

Written evidence should contain a brief introduction to the persons or organisations submitting it.

Submissions should take the form of a memorandum, which should have numbered paragraphs and should not exceed 3000 words in length. Unless submissions are very short, they should be accompanied by a summary.

Those submitting evidence on behalf of organisations are encouraged to indicate whether procedures exist for testing the opinion of members and, if so, whether such procedures have been invoked recently.

Evidence should, if possible, be submitted, in MS Word or rich text format, by e-mail to assisteddyingbill@parliament.uk. A single hard copy (single-sided, unbound) should also be sent to Select Committee on the Assisted Dying for the Terminally Ill Bill [HL], Committee Office, House of Lords SW1A 0PW. If you would find it difficult to submit evidence in this way, please contact the Committee staff at the addresses shown below to discuss alternatives.

Once written evidence has been submitted it becomes the property of the Committee.

Those who have submitted written evidence to the Committee are welcome to publish their evidence themselves (for example, by placing it on their own websites), provided that it is not published until after the Committee has acknowledged receipt of the evidence and that it is made clear that the document was prepared as evidence to the Committee.

Written submissions from those invited to give oral evidence will be available at the relevant hearing. Written evidence will, wherever possible, be posted on the Committee's webpages, and then either published by the Committee with its final Report or placed in the public domain when that Report is published.

Those considering submitting information that they would wish the Committee to treat as confidential should consult the Committee staff in advance, initially by sending an e-mail to the address given at the end of this letter.

In addition to this call for formal evidence, individuals may make their views on the Bill known by sending a short letter or email to the address given at the end of this letter. Such letters or emails should state the sender's name and address and his or her reasons (in brief) for either supporting or opposing the Bill. Alternatively, instead of setting out their reasons, they may wish simply to associate themselves with the views of one or another organisation.

Enquiries in connection with the submission of written evidence and short letters or emails from individuals should be addressed to:

Select Committee on the Assisted Dying for the Terminally Ill Bill
Committee Office
House of Lords
London SW1A 0PW
Email: assisteddyingbill@parliament.uk
Tel. 020-7219-4568

Membership

The members of the Committee are as follows:

Earl of Arran
Lord Carlile of Berriew
Baroness Finlay of Llandaff
Baroness Hayman
Baroness Jay of Paddington
Lord Joffe
Lord McColl of Dulwich
Lord Mackay of Clashfern (*Chairman*)
Lord Patel
Bishop of St Albans
Lord Taverne
Baroness Thomas of Walliswood
Lord Turnberg

APPENDIX 3: LIST OF WITNESSES

The following witnesses gave evidence. (w) denotes written evidence, (o) denotes oral evidence.

Organisations

- (w) Affinity (British Evangelical Council)
- (w) ALERT
- (w,o) Association for Palliative Medicine of Great Britain and Ireland
- (w,o) Association of British Neurologists
- (w) Association of Catholic Nurses for England and Wales
- (w) Association of Catholic Women
- (w) Association of Hospice and Palliative Care Chaplains
- (o) The Attorney General for the Canton of Zurich
- (w) British Association of Social Workers
- (w,o) British Geriatrics Society
- (w,o) British Humanist Association
- (w,o) British Medical Association
- (o) British Psychological Society
- (w) CARE
- (w) Catholic Union of Great Britain
- (w,o) Catholic Bishops Conference of England and Wales
- (w,o) Church of England House of Bishops
- (w,o) Centre of Medical Law and Ethics, King's College London
- (w) Christian Medical Fellowship
- (w) College of Health Care Chaplains
- (w,o) Department of Health
- (w,o) Dignitas
- (w,o) Disability Awareness in Action
- (w,o) Disability Rights Commission
- (w,o) EMGO Institute, Amsterdam
- (o) EXIT
- (o) Federal Ministry of Justice, Switzerland
- (w) Friends at the End
- (w,o) General Medical Council
- (w) George House Trust
- (w) Guild of Catholic Doctors
- (w,o) Help the Aged

- (w) Help the Hospices
- (w) Linacre Centre for Healthcare Ethics
- (w) Macmillan Cancer Relief
- (w) Marie Curie Cancer Care
- (w) Medical Ethics Alliance
- (w) Methodist Church
- (o) Ministry of Health, Welfare and Sport (NL)
- (w) Modern Churchpeople's Union
- (w,o) Motor Neurone Disease Association
- (w,o) National Council for Hospice and Specialist Palliative Care Services
- (w) Nursing and Midwifery Council
- (w,o) NVVE (Right to Die-NL)
- (w,o) Office of the Chief Rabbi
- (w,o) Oregon Department of Human Services
- (w,o) Oregon Health and Sciences University
- (w,o) Oregon Hospice Association
- (w,o) Policy, Ethics and Life Sciences Research Institute, University of Newcastle
- (o) Regional Case Assessment Committee (The Hague)
- (w,o) Right to Life
- (w) Royal College of Anaesthetists
- (w,o) Royal College of General Practitioners
- (w,o) Royal College of Nursing
- (w) Royal College of Paediatrics and Child Health
- (w) Royal College of Pathologists
- (w,o) Royal College of Physicians
- (w) Royal College of Physicians of Edinburgh
- (o) Royal College of Psychiatrists
- (w) Royal College of Surgeons
- (w,o) Royal Dutch Medical Association (KNMG)
- (w) Royal Marsden NHS Foundation Trust
- (w) Scottish Partnership for Palliative Care
- (o) Sint Jacob's Hospice, Amsterdam
- (o) Swiss Academy of Medical Sciences
- (o) Swiss National Advisory Commission of Biomedical Ethics
- (w) Terrence Higgins Trust
- (w) Universiteit Antwerpen (UFSIA)
- (w,o) Voluntary Euthanasia Society

(w) Vrije Universiteit Brussel

Witnesses giving evidence in a personal capacity

Ms Karen Bell

Dr Jon Bos

Dr Georg Bosshard

Dr Nico Mensingh van Charante

Dr Ruben van Coevorden

Dr David Cole

Ms Barbara Coombs Lee

Dr Carole Dacombe

Ms Alison Davis

Professor van den Eynden

Dr Darien Fenn

Professor John Finnis

Professor Kathleen Foley

Dr Nick Gideonse

Dr Jim Gilbert

Baroness Greengross

Ms Marjo Gribling-Gommans

Dr Greg Hamilton

Professor Henk Jochemsen

The Lord Joffe

Dr Maria van den Muijsenburgh

Professor Timothy Quill

Dr Fiona Randall

Dr Peter Rasmussen

Dr Dirk Raymakers

Dr Robert H. Richardson

Dr Kenneth Stevens

Mr Ron Sunseri

Professor Raymond Tallis

Dr William Toffler

The Lord Walton of Detchant

Ms Michele Wates

Professor Guy Widdershoven

Dr Ben Zylicz

APPENDIX 4: TEXT OF THE ASSISTED DYING FOR THE TERMINALLY ILL
BILL [HL]

Assisted Dying for the Terminally Ill Bill [HL]

CONTENTS

- 1 Authorisation of assisted dying
- 2 Qualifying conditions
- 3 Offer of palliative care
- 4 Declaration made in advance
- 5 Further duties of attending physician
- 6 Revocation of declaration
- 7 Duties of physicians, and conscientious objection
- 8 Psychiatric referral
- 9 Notification of next of kin
- 10 Protection for physicians and other medical personnel
- 11 Offences
- 12 Insurance
- 13 Requirements as to documentation in medical records
- 14 Monitoring commission and reporting requirements
- 15 Administration of drugs to patients suffering severe distress
- 16 Power to make regulations
- 17 Short title and extent

Schedule — Form of declaration

A

Bill

TO

Enable a competent adult who is suffering unbearably as a result of a terminal illness to receive medical assistance to die at his own considered and persistent request; and to make provision for a person suffering from a terminal illness to receive pain relief medication.

BE IT ENACTED by the Queen's most Excellent Majesty, by and with the advice and consent of the Lords Spiritual and Temporal, and Commons, in this present Parliament assembled, and by the authority of the same, as follows:—

1 Authorisation of assisted dying

(1) Subject to the provisions of this Act, it shall be lawful for a physician to assist a patient who is a qualifying patient, and who has made a declaration in accordance with this Act that is for the time being in force, to die.

(2) For the purposes of this Act—

“assisted dying” means the attending physician, at the patient's request, either providing the patient with the means to end the patient's life or if the patient is physically unable to do so ending the patient's life;

“attending physician” means the physician who has primary responsibility for the care of the patient and the treatment of the patient's illness;

“competent” means having the capacity to make an informed decision, and “competence” shall be construed accordingly;

“consulting physician” means a consultant physician practising in the National Health Service who is qualified by speciality to make a professional diagnosis and prognosis regarding the patient's illness and who is independent of the attending physician;

“declaration” means a witnessed declaration in writing made by the qualifying patient in the form set out in the Schedule to this Act, as amended from time to time by regulations;

“incompetent” means not having the capacity to make an informed decision, and “incompetence” shall be construed accordingly;

“informed decision” means a decision by a qualifying patient to request medical assistance to die, which is based on an appreciation of the relevant facts and after being fully informed by the attending physician, and the consulting physician (save in respect of (c) below), of—

- (a) his medical diagnosis;
- (b) his prognosis;

(c) the process of being assisted to die; and

(d) the alternatives, including, but not limited to, palliative care, care in a hospice and the control of pain;

“medical care team” means a person or persons assisting the attending physician in the provision of medical care to a patient, and includes but without limitation a nurse or pharmacist;

“monitoring commission” means a commission set up by the Secretary of State to monitor the workings of this Act in a country or region forming a part of Great Britain;

“patient” means a person who is under the care of a physician;

“physician” means a registered medical practitioner;

“qualifying conditions” means those conditions set out in sections 2, 3, 4 and 5;

“qualifying patient” means a patient who has reached the age of majority, who has been resident in Great Britain for not less than twelve months as at the date of the declaration and in respect of whom all the qualifying conditions under sections 2, 3, 4 and 5 are met;

“terminal illness” means an illness which in the opinion of the consulting physician is inevitably progressive, the effects of which cannot be reversed by treatment (although treatment may be successful in relieving symptoms temporarily) and which will be likely to result in the patient’s death within a few months at most;

“unbearable suffering” means suffering whether by reason of pain or otherwise which the patient finds so severe as to be unacceptable and results from the patient’s terminal illness; and “suffering unbearably” shall be construed accordingly;

“waiting period” means that period of time between the date on which the patient first informed the attending physician that the patient wishes to be assisted to die in accordance with section 2(2)(a) and the date on which the patient is assisted to die, and such period shall not be less than 14 days in all; and “witness” means a person who signs by way of attestation a declaration made under section 4.

2 Qualifying conditions

(1) Before the attending physician can assist a qualifying patient to die the conditions specified in this section and sections 3, 4 and 5 must be satisfied.

(2) The attending physician shall have—

(a) been informed by the patient that the patient wishes to be assisted to die;

(b) examined the patient and the patient’s medical records and have no reason to believe the patient is incompetent;

(c) made a determination that the patient has a terminal illness;

(d) concluded that the patient is suffering unbearably as a result of that terminal illness;

(e) informed the patient of—

- (i) his medical diagnosis;
 - (ii) his prognosis;
 - (iii) the process of being assisted to die;
 - (iv) the alternatives, including, but not limited to, palliative care, care in a hospice and the control of pain;
 - (f) if the patient persists with his request to be assisted to die, satisfied himself that the request is made voluntarily and that the patient has made an informed decision; and
 - (g) referred the patient to a consulting physician.
- (3) The consulting physician shall have—
- (a) been informed by the patient that the patient wishes to be assisted to die;
 - (b) examined the patient and the patient's medical records and satisfied himself that the patient is competent;
 - (c) confirmed the diagnosis and prognosis made by the attending physician;
 - (d) concluded that the patient is suffering unbearably as a result of the terminal illness;
 - (e) informed the patient of the alternatives including, but not limited to, palliative care, care in a hospice and the control of pain;
 - (f) if the patient still persists with his request to be assisted to die, satisfied himself that the request is made voluntarily and that the patient has made an informed decision; and
 - (g) advised the patient that prior to such assistance the patient will be required to complete a declaration which the patient can revoke.

3 Offer of palliative care

- (1) The attending physician shall ensure that a specialist in palliative care who shall be a physician or nurse has attended the patient to discuss the option of palliative care.
- (2) Only once the requirements of sections 2(2), 2(3) and 3(1) have been satisfied may the patient make the declaration in the form set out in the Schedule.

4 Declaration made in advance

- (1) When the conditions set out in sections 2 and 3 have been met, a patient who wishes to be assisted to die must make a declaration in the form set out in the Schedule.
- (2) The declaration must be witnessed by two individuals one of whom shall be a solicitor who holds a current practising certificate.
- (3) The solicitor may only witness the declaration if—
 - (a) the patient is personally known to the solicitor or has proved his identity to the solicitor;

- (b) it appears to the solicitor that the patient is of sound mind and has made the declaration voluntarily; and
 - (c) the solicitor is satisfied that the patient understands the effect of the declaration.
- (4) The other witness may only witness the declaration if—
- (a) the patient is personally known to that witness or has proved his identity to that witness; and
 - (b) it appears to that witness that the patient is of sound mind and has made the declaration voluntarily.
- (5) The patient and witnesses shall sign and witness the declaration respectively at the same time and each in the presence of the others.
- (6) The attending or consulting physician, psychiatrist or member of the medical care team, or a relative or partner (by blood, marriage or adoption) of the qualifying patient signing this request may not witness the declaration.
- (7) No person who owns, operates or is employed at a health care establishment where the person is a patient or resident may witness the declaration.
- (8) The declaration shall come into force after the requisite waiting period has elapsed and shall remain in force (unless revoked) for six months.

5 Further duties of attending physician

Before taking any step to assist the patient to die the attending physician shall have—

- (a) informed the patient of his right to revoke the declaration;
- (b) verified immediately before assisting the patient to die that the declaration is in force and that it has not been revoked by the patient; and
- (c) asked the patient immediately before assisting him to die whether he wishes to revoke the declaration.

6 Revocation of declaration

- (1) A patient may revoke his declaration whether orally or in any other manner without regard to his physical or mental state.
- (2) In the event of a declaration being revoked, the attending physician shall ensure that a note recording its revocation is made on the patient's file and that the declaration is removed from the patient's medical file and destroyed.

7 Duties of physicians, and conscientious objection

- (1) No person shall be under any duty, whether by contract or by any statutory or other legal requirement, to participate in any diagnosis, treatment or other action authorised by this Act to which he has a conscientious objection.
- (2) If an attending physician whose patient makes a request to be assisted to die in accordance with this Act or to receive pain relief under section 15 has a conscientious objection as provided in subsection (1), he shall take appropriate

steps to ensure that the patient is referred without delay to an attending physician who does not have such a conscientious objection.

- (3) If a consulting physician to whom a patient has been referred in accordance with section 2(2)(g) has a conscientious objection as provided in subsection (1), he shall take appropriate steps to ensure that the patient is referred without delay to a consulting physician who does not have such a conscientious objection.

8 Psychiatric referral

- (1) If in the opinion of either the attending or the consulting physician a patient who wishes to make or has made a declaration may not be competent, the attending physician shall refer the patient to a psychiatrist for a psychiatric opinion.
- (2) No assistance to end that patient's life may be given unless the psychiatrist has determined that the patient is not suffering from a psychiatric or psychological disorder causing impaired judgement, and that the patient is competent.

9 Notification of next of kin

The attending physician shall recommend to the patient that the patient notifies his next of kin of his request for assistance to die.

10 Protection for physicians and other medical personnel

- (1) A physician, acting in good faith, who assists a qualifying patient to die, or attempts to do so, in accordance with the requirements of this Act, shall not be guilty of an offence.
- (2) A member of a medical care team, acting in good faith, who helps a physician to assist a qualifying patient to die, or to attempt to do so, in accordance with what he reasonably believes to be the requirements of this Act, shall not be guilty of an offence.
- (3) A physician to whom subsection (1) applies or, as the case may be, a member of a medical care team to whom subsection (2) applies, shall be deemed not to be in breach of any professional oath or affirmation.
- (4) No physician, psychiatrist or member of a medical care team may take any part whatsoever in assisting a qualifying patient to die, or in giving an opinion in respect of such a patient, nor may any person act as a witness, if he has grounds for believing that he will benefit financially or in any other way as the result of the death of that patient.

11 Offences

- (1) A person commits an offence if he wilfully falsifies or forges a declaration made under section 4 with the intent or effect of causing the patient's death. A person guilty of an offence under this subsection shall be liable, on conviction on indictment, to imprisonment for life or for any shorter term.

- (2) A witness commits an offence if he wilfully puts his name to a statement he knows to be false. A person guilty of an offence under this subsection shall be liable on conviction to imprisonment for a term not exceeding five years.
- (3) A person commits an offence if he wilfully conceals or destroys a declaration made under section 4. A person guilty of an offence under this subsection shall be liable on conviction to imprisonment for a term not exceeding five years.
- (4) A physician, psychiatrist, member of a medical care team or witness commits an offence if he contravenes the requirements of section 10(4). A person guilty of an offence under this subsection shall be liable on conviction to imprisonment for a term not exceeding five years.
- (5) No provision of this Act shall be taken to affect a person's liability on conviction to criminal penalties for conduct which is inconsistent with the provisions of this Act.

12 Insurance

No policy of insurance which has been in force for 12 months as at the date of the patient's death shall be invalidated by reason of a doctor having assisted a qualifying patient to die in accordance with this Act.

13 Requirements as to documentation in medical records

- (1) The attending physician shall ensure that the following are documented and filed in the patient's medical records—
 - (a) all evidence, data and records which demonstrate that the qualifying conditions required under sections 2, 3, 4 and 5 have been met;
 - (b) any oral or written requests by the patient for assistance to end his life;
 - (c) the declaration; and
 - (d) a note by the attending physician stating that he was satisfied, at the date and time of his having assisted the patient to die, that all requirements under this Act had been met and indicating the steps taken to carry out the declaration including the description and quantity of the medication prescribed.
- (2) The attending physician shall send a full copy of the file to the monitoring commission for the country or region concerned within seven days of the qualifying patient having been assisted to die or of an attempt so to assist having been made.

14 Monitoring commission and reporting requirements

- (1) There shall be established such number of monitoring commissions covering countries or regions forming part of Great Britain as the Secretary of State may determine, to review the operation of this Act and to hold and monitor records maintained pursuant to this Act.
- (2) A monitoring commission shall consist of three members appointed by the Secretary of State, of whom—
 - (a) one shall be a registered medical practitioner;

- (b) one shall be a legal practitioner; and
 - (c) one shall be a lay person having first hand knowledge or experience in caring for a person with a terminal illness.
- (3) If, in relation to a file sent to a monitoring commission in accordance with section 13(2), two of its members consider that the qualifying conditions have not been met, they shall refer the matter to the district coroner or in Scotland to the procurator fiscal for further investigation.
- (4) A monitoring commission to which a file has been sent in accordance with section 13(2) shall confirm to the attending physician concerned whether the qualifying conditions have been met as soon as reasonably possible after the date of receiving such notification of the patient having been assisted to die whether or not such assistance led to the patient's death.
- (5) The Secretary of State shall publish an annual statistical report of information collected under this section.

15 Administration of drugs to patients suffering severe distress

A patient suffering from a terminal illness shall be entitled to request and receive such medication as may be necessary to keep him free as far as possible from pain and distress.

16 Power to make regulations

- (1) The Secretary of State may make regulations under this Act—
- (a) to ensure the intent of this Act is carried out;
 - (b) determining classes of persons who may or may not witness a declaration made under section 4;
 - (c) regulating the custody of records and the collection of information regarding the operation of this Act; and
 - (d) making provision about appointments to and the operation of the monitoring commissions.
- (2) The power to make regulations under this Act is exercisable by statutory instrument.
- (3) No statutory instrument may be made under this Act unless a draft of the instrument has been laid before, and approved by a resolution of, each House of Parliament.

17 Short title and extent

- (1) This Act may be cited as the Assisted Dying for the Terminally Ill Act 2004.
- (2) This Act does not extend to Northern Ireland.

SCHEDULE

Section 1

FORM OF DECLARATION

Declaration made _____ 20__
by [_____]
of [_____]

I, _____, am an adult of sound mind who has been resident in Great Britain for at least twelve months as at the date of this declaration.

I am suffering from _____, which my attending physician, Dr _____, has determined is a terminal illness and which has been confirmed by a consulting physician, Dr _____.

I have been fully informed of my diagnosis, prognosis, the process of being assisted to die, and the alternatives, including palliative care, care in a hospice and the control of pain.

I request that my attending physician assist me to die.

I make this request voluntarily and without reservation.

Please delete as appropriate:

I have decided to inform / not to inform my family of my decision.

I understand that I have the right to revoke this declaration.

Signed: _____

Date: _____

DECLARATION OF WITNESSES

I declare that I am a solicitor with a current practising certificate and that the patient signing this request:

- (a) is personally known to me or has proved his identity to me;
- (b) signed or made his mark confirming that this was his request in my presence;
- (c) appears to be of sound mind and to have made the declaration voluntarily; and
- (d) appears to understand the effect of the declaration.

Witness 1

Date

I declare that the person signing this request:

- (a) is personally known to me or has proved his identity to me;
- (b) signed or made his mark confirming that this was his request in my presence; and
- (c) appears to be of sound mind and to have made the declaration voluntarily.

Witness 2

Date

Notes

1. One of the witnesses must be a solicitor with a current practising certificate who has satisfied himself that the patient understands the effect of the declaration.
2. The patient and witnesses shall sign and witness the declaration respectively at the same time and each in the presence of the others.
3. The attending or consulting physician, psychiatrist or member of the medical care team, or a relative or partner (by blood, marriage or adoption) of the qualifying patient signing this request may not be a witness.
4. No person who owns, operates or is employed at a health care establishment where the person is a patient or resident may be a witness.

APPENDIX 5: MOTOR NEURONE DISEASE—SYMPTOMS AND TREATMENT

NOTE BY DR RICHARD HILLIER

Introduction

Motor Neurone Disease (MND) is a rare, incurable and invariably fatal condition. Many would consider it worse than cancer. Because of its slow, relentless course, it has attracted considerable attention within the assisted dying debate.

It is characterised by gradually increasing weakness, initially of the limbs, and culminates in complete paralysis so that the patient depends on others for every activity of daily living. Ultimately, only the eye muscles may be spared, although 85% of patients normally retain control of bowel and bladder. Sensation remains normal: pain is only a later consequence. Most patients retain complete intellectual function although depression occurs in 7% to 50% of them, dementia in 10% and significant cognitive impairment in some.

Incidence and Prevalence

Across the United Kingdom, there are between 1.5 and 2 new patients diagnosed with MND per 100,000 population per year. There are approximately 1000 deaths from the condition per year. In some areas of the United Kingdom, e.g. West Sussex, there is an unexplained prevalence. A general practitioner with a list of 2000 patients might expect to have 1 or 2 patients in his/her own professional lifetime, but a group practice of, say, 5 doctors may obviously see more. Because of the rarity of MND, there are few neurologists who specialise in its management. The same is true of palliative medicine physicians.

The literature: strength of evidence

Most of the sparse literature on the symptom control, management and patients' /carers' views about the disease and assisted suicide consists of descriptive surveys or editorials. There is very little data evaluating the effects of symptom control on patients' quality of life in MND. There are two original articles on assisted dying from Oregon [1] and The Netherlands [8].

How does MND affect patients?

In addition to increasing weakness and associated muscle cramps, symptoms reported by carers towards the end of life include gradual loss of speech (62%), choking episodes (52%), breathlessness (50%), insomnia (42%), discomfort other than pain (48%), depression (40%) and anxiety (30%) [1]. Others mention drooling, cough and fear. In Oregon, 30% of patients are supported by a hospice.

In the United Kingdom, of 170 hospices surveyed, all provided in-patient care, 60% provided care at home, 76% provided hospice day-care and support for 28% in hospital. Of these hospices, 17% became involved at the time of diagnosis, rising to 48% in the terminal stages [2].

Symptoms that are particularly difficult

Surprisingly, most of the symptoms mentioned above can be relieved or reduced to some extent but the effect of treatment overall has not been studied in randomised controlled trials. Some services in the United Kingdom and Germany have

produced clear guidelines for management. The Association of British Neurologists has identified standards of care for MND.

Fear

Publicity and media stories about MND, coupled with the graphic horror of a relentlessly paralysing disease which ends in death, ensures that at diagnosis most patients are frightened. The fear is always real and often leads to anxiety and depression. It is incumbent on the physician to provide explanations in order to diminish this fear. For example, there is no pain at this stage, discomfort can be relieved by good physiotherapy and appropriate drugs, intellectual capacity remains unimpaired, and the feared incontinence is rarely a problem. Even at this stage, involvement of a full multi-professional expert team should be instigated as the burden of this condition on both patients and families will be considerable.

Choking

Patients will have read that this happens and will have heard it reported in the media; and the Committee has heard the evidence of Dr Taylor who said, "I shall die of pneumonia caused by the inhalation of saliva". With this in the public perception, the first coughing fit or sensation of choking often causes inordinate terror and requires extremely careful management and reassurance, particularly about the end stage of life.

What are the facts? Of 124 patients with MND cared for in a London hospice, only one appeared to choke to death. Autopsy revealed however that that patient had died, not of MND, but of myocardial infarction [3]. In this patient and 19 others who had autopsies, none had any foreign matter in the mouth, throat or breathing tubes. In another study by the caregivers of 121 patients in Germany, no patient choked to death [4]. Ganzini's study of the views of caregivers was significantly different [1].

How then do they die?

The majority of MND patients die of respiratory failure. What occurs is that the muscles which affect breathing gradually weaken. Over time this creates a build-up of carbon dioxide in the blood which, instead of stimulating breathing, actually depresses it with the result that the patient, in effect, dies in his/her sleep. This often occurs in previously stable patients and can be quite sudden. Of 113 patients dying in a London hospice, 48% deteriorated suddenly and died within 24 hours. Only 2% survived longer than one week [3].

Although it is possible to put patients on a ventilator, this option is rarely discussed because the necessary resources are often not available. Less than 2% of patients in the United Kingdom accept ventilation: only 2.9% of patients in New York did so.

Diagnosis and Management

It is crucial that an accurate diagnosis of MND is made at the outset because there are a number of treatable neurological conditions which can mimic it, e.g. myasthenia gravis. The diagnosis must be made by a neurologist and, even then, a second opinion may be required.

Management consists of three aspects:

- Relief of pain and symptoms
- Management of the physical effects of the disease, e.g. paralysis
- Psychological and emotional support of patients and families

There are a few drugs under trial to slow progression of the disease, but so far these have not been remarkable and their effects have not been evident to either the patient or his/her family as the disease progresses.

Food and fluids

In the late stages of the disease, swallowing may become difficult to some extent, although this is not invariable. Expert speech and language therapists can successfully teach patients new techniques to deal with this. Because these therapists are not commonly involved, more patients than necessary have a feeding tube inserted through the stomach wall—a painless and effective procedure.

Most of the symptoms can be helped or relieved but there are no randomised controlled trials to measure this. Nevertheless considerable interest and progress has been made in the general management of MND over the past ten years. Because general practitioners see patients with this condition only rarely, MND should be managed in a centre with a specialist MND team consisting of a physician, nurses, occupational therapist, physiotherapist, social worker, speech and language therapist and counsellors, who can work with the primary health care team in offering patient and family care and support. Palliative care teams are increasingly involved and combined clinics with neurologists and palliative care specialists are becoming more available. Involvement with the MND Association, which can provide invaluable advice and respite, is essential.

When the above exists and is coordinated well, the care and support for patients and families can be superb. Unfortunately such centres are rare (though increasing) and patients who are not involved can suffer considerably.

Some questions concerning MND

How effective is palliative care?

In a properly constituted team, it can be good. Anecdotal evidence suggests that many symptoms can be relieved, fear of dependency and choking can be diminished, and pro-active management can prevent the occurrence of many problems. Obviously, not all suffering can be relieved.

Can palliative care relieve depression?

Yes, provided it is diagnosed and that treatment (drug and non-drug) is given.

Can palliative care relieve “loss of self-worth”?

Of 56 patients, 84% of those who did not want PAS, and 52% of those who would, looked forward to the future with “hope and enthusiasm” [6].

Does morphine in these patients shorten life?

In cancer patients, the starting dose of morphine for pain control is 30-60 mg per day and may rise up to, and even beyond, 1000 mg per day with the patient remaining conscious, alert and active. In one study of patients with MND,

symptoms were controlled with a morphine mean dose of 60 mg per day [7]; in another study, the mean dose was 30 mg per day in MND patients [3]. There is no evidence that morphine shortens life when used appropriately in these patients, nor that excessively high doses are needed to control their pain.

Is the issue of PAS for MND and other non-cancer conditions different from the issues concerning patients with cancer?

To some extent. Prognosis is often longer for MND, and can be longer if artificial ventilation is used (up to 17 years) [5]. Assessment of depression/competence may be more difficult in a patient if left too late. As one patient said “don’t let go too soon but don’t hang on too long”. Being a rare disease, the burden on the attending or consulting physician may fall on very few specialists and distort clinical practice.

In countries where it is legal, what proportion of patients seek or accept assisted suicide?

In the Netherlands, 20% of 203 patients with MND received euthanasia or PAS [8]. In a study in Oregon, 56% of 100 patients said they would consider assisted suicide. In 73% of these, caregivers and patients agreed. Many would request a prescription well before they would use it [6].

Is prognosis a problem?

In MND, deterioration is often rapid. As mentioned previously, 50% may deteriorate suddenly and die in 24 hours [3] and it is hard to anticipate this. There is no objective measure and the assessment of prognosis is a combination of experience and professional judgment in consultation with others who know the patient well.

1. Ganzini et al., 2002, Neurology, Vol. 59, p.428-431.
2. Oliver et al, 2000, Palliative Medicine, Vol. 14, p. 427-8.
3. O’Brien, 1992, British Medical Journal, Vol. 304, p. 471-3.
4. Neudert et al, 2001, Journal of Neurology, Vol. 248, p. 612-6.
6. Ganzini et al, 1998, New England Journal of Medicine, Vol. 339, p. 967-73.
7. Oliver, 1998, Palliative Medicine, Vol. 12, p. 113-5.
8. Veldink, 2002, New England Journal of Medicine, Vol. 346, p. 1638-44.

Some relevant papers and websites consulted:

Borasio et al, 1997, Journal of Neurology, Vol. 244, p. SII-SI7. Miller et al, 1999, Neurology, Vol. 52, p.1311-23.

Howard et al, 2002, Postgraduate Medical Journal, Vol. 78, p. 736-41.

Association of British Neurologists: info@theabn.org

APPENDIX 6: NVVE EUTHANASIA STATEMENT

EUTHANASIA STATEMENT

NAME

DATE OF BIRTH

PLACE OF BIRTH

MEMBERSHIP NUMBER

By this directive I address myself to the physician treating me.

1 BASIC CRITERION

After thorough consideration I do not wish to live further if I should come to be in:

- a a condition of unbearable suffering, and/or
- b a condition which provides little or no prospect of a return to what is for me a reasonable and dignified existence

By the latter condition I mean in any event:

- a coma lasting longer than <..> weeks;
- a permanent vegetative state (living mindlessly);

2 REQUEST FOR HELP IN ORDER TO BE ABLE TO DIE

If I am in a condition as referred to in point 1 (a) or (b), **I urgently request the physician treating me to fulfil my death wish** by allowing me to take substances under his or her supervision—or, if I am no longer able to do so, to administer to me substances—that will bring about a mild death.

3 REFERRAL

If the physician treating me in the circumstances referred to at 1 is unwilling or unable to comply with my above-mentioned request, I request him or her to refer me immediately to another physician who is willing and able to do so.

4 DUTY OF SECRECY

If my request has been complied with, an investigation into my death will be instituted by the authorities. I release the physician treating me from his or her duty of secrecy regarding my medical particulars. I request him or her to provide the particulars needed for that investigation.

5 RISK OF ACCEPTANCE

This directive will remain in force irrespective of the period that has elapsed since its signature. I therefore consciously accept the risk that I may later wish to amend

or revoke it, but am then no longer able to do so. I do this in order to exclude a greater risk, namely that I should have to continue living in circumstances that are not acceptable to me.

6 DEPOSIT

I will deposit a copy of this directive with my family doctor or any other physician treating me and with my representative (or deputy representative).

7 REPLACEMENT

I hereby replace my previous euthanasia statements.

The oldest of them was signed on <.....>.

8 SIGNATURE

I have given careful thought to this directive and to the additions signed to me. I am very clear about my wishes on medical matters. To use the terms of the law, I am "able to make an informed decision about my interests in this respect".

PLACE

DATE

SIGNATURE

9 ADDITIONS

In so far as they are **ticked** and **signed**, I understand the following to be included in the situations referred to in point 1:

a: a life with serious, permanent paralysis.

DATE

SIGNATURE

b: being totally dependant on other persons for such general daily activities as eating, drinking, going to the lavatory, dressing and undressing.

DATE

SIGNATURE

c: having a handicap such as being blind or virtually blind and/or deaf and/or virtually deaf which make it impossible or virtually impossible for me to perform what are for me worthwhile activities such as reading, writing, watching television, listening to music, and doing manual work or handicrafts.

DATE

SIGNATURE

d: having a severe impairment or continuing degeneration of my mental faculties, as a result of which I, for example,

- no longer know who I am or where I am,

- have lost my capacity to communicate;
- no longer recognise those dear to me;
- must be confined because I would otherwise go wandering.

DATE

SIGNATURE

10 PERSONAL ADDITION (only if ticked and signed)

Owing to my personal circumstances I have written an addition to this directive. The addition is attached to this directive and forms part of it.

DATE

SIGNATURE

APPENDIX 7: PUBLIC OPINION ON THE LEGALISATION OF EUTHANASIA/PAS: A RESEARCH REVIEW CARRIED OUT BY MARKET RESEARCH SERVICES, DECEMBER 2004

FOREWORD: BRIEF SUMMARY OF FINDINGS

1. This report summarises available research findings, mainly focused on the last 10 years or so, on the subject of attitudes to the legalisation of euthanasia and physician-assisted suicide among the general public and the health sector.
2. The findings should be treated with great caution. Very little research exists which is built on techniques appropriate for so complex and sensitive a subject as euthanasia and whether/how it should be legalised. Research sponsors frequently appear to have been more concerned to achieve statistics for media consumption than to work towards achieving a comprehensive understanding of public and health sector attitudes.
3. Among the general public, research findings over many years suggest, at least at face value, that there is a widespread and growing concern to legalise the situation of the terminally ill who wish to die and those prepared to help them.
4. Opposition to the legalisation of euthanasia/PAS is most readily linked to “religious” attitudes to life as sacred. The concept of passive euthanasia (withdrawal/withholding of treatment) appears as relatively uncontentious.
5. The concept of Living Wills is generally supported in the small amount of mention given, though there is some feeling that doctors should not necessarily be *obliged* to follow them.
6. Views on potential implications of legalising euthanasia/PAS, for specific groups of individuals and for society in general emerge only in occasional strands of research. There are suggestions that older people may become nervous of entering hospital and that those who are dependent on others may feel motivated to request euthanasia. There are marginal suggestions that trust in doctors and nurses may suffer some erosion.
7. Disabled people’s views are not clear from the sources which are less than adequate for the purpose and tend to be somewhat contradictory in their findings.
8. Public involvement in decisions around the legalisation of euthanasia/PAS is requested strongly (referendum) in surveys in Isle of Man and Guernsey, but not explored elsewhere.
9. Illegal euthanasia was also thought to sometimes occur by very many on these two islands, but the question does not feature in mainland research.
10. Politicians’ views of the legalisation of euthanasia/PAS appear to differ markedly from those of the general public, with only a diminishing minority in favour.
11. Doctors also appear to be notably less in favour of legalising euthanasia than the general public. Variations in the format and in the quality of research into medical sector views make summary difficult. At “face value”, the results suggest that support for legalising euthanasia is diminishing latterly, after expanding over a number of years.
12. Euthanasia/PAS appears to be an area of difficulty and dilemma for doctors. Many have received requests to provide help but the data varies as to how

many have helped patients wishing to die to do so. Most doctors appear to believe that the incidence of illegal euthanasia/PAS is small, but sources vary somewhat. There is some suggestion that those who have been asked to provide help to die are more open than others to the concept of legal reform. GPs appear generally to be more open to reform than hospital specialists.

13. Geriatricians form the only specific medical group who appear, in one study, as strongly opposed to legal reform, principally because of potential pressure on old people to request euthanasia—and a sense that the social processes of dying and grieving might become undermined.

14. Nurses' views are not very visible. A recent *Nursing Times* readership poll (for which satisfactory details were not available) suggested that 2:3 nurses would like euthanasia to be legalised.

15. Pharmacists' views appear (from one limited study) to be largely in line with doctors—less than half were in favour of legalising PAS. The sample was split on whether they should/would willingly dispense drugs for suicide.

16. The palliative care sector is represented in one qualitative study, which suggests that, although some support the concept of legalised euthanasia, there are many concerns about the potential impact on care and on relationships between doctors, carers and patients.

17. The key conclusion of this report is that, although *some* idea of the basic attitude of the general public is available through research sources, this does not amount to an authentic picture of public opinion which is in any way comprehensive. Deliberative research techniques, unused so far for this subject, which can produce an account of *informed* public opinion, are recommended if a proper understanding of public opinion is to be achieved. This suggestion is also made with regard to the health sector, where much of the research carried out has been too limited in value to rely on for the purposes of informing decisions on the reform of current legislation.

1. INTRODUCTION

The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill requested a survey to be carried out of any existing sources of information on public attitudes to euthanasia and physician-assisted suicide (PAS), including the attitudes of those in the health sector.

The objectives of the study were to:

- identify what research had been carried out in recent years into public attitudes to euthanasia/PAS
- to provide an account of the main findings as relevant to the Committee's purposes
- as far as feasible, to examine each element of research and make a judgement as to its validity, relevance and usefulness for understanding public and health sector attitudes to the given topic

Some research sources were identified in advance by the Clerk to the Committee and others by COI Communications. Others became apparent in the course of following up initial sources and through internet searches. The Voluntary Euthanasia Society was particularly helpful in identifying relevant pieces of research, as was the Pro-life Alliance and a range of other individuals who had

been involved in commissioning, carrying out or publicising specific research projects.

Note on terminology: In general, the concepts of “euthanasia”—*active* euthanasia, unless otherwise stated—and “physician-assisted suicide” are distinguished wherever the data allows. Only in some of the data are the two potential roles of the doctor distinguished—providing drugs/information for suicide or, at the patient’s request, administering drugs calculated to kill. Essentially, the debate is about the concept of doctors helping very sick patients who wish to die, to do so at a time of the patient’s choosing, and it is to this over-riding concept that the term “euthanasia” mainly refers when used without qualification.

2. RESEARCH SOURCES

A list of the main research sources consulted for this project appears as an appendix. These are numbered and are frequently referred to by number throughout the text.

Overall, there is not a great deal of reliable detailed guidance available as to attitudes to euthanasia/PAS, especially among the general public. Virtually all the studies identified are quantitative in nature, drawing upon a variety of sample sizes and types, some clearly more adequate than others. In general, both the questions posed and the analysis of the responses tend to be limited in scope. There is little evidence of the employment of in-depth exploratory research techniques such as would conventionally be used to provide an initial understanding, especially of complex, sensitive topics such as euthanasia/PAS, to guide survey design and fuel the understanding of quantitative results.

As a result, the quantitative techniques employed, which by definition are capable of providing breadth more than any depth of understanding, often tend to produce findings which at best may be considered one-dimensional. Simple, direct questions, placed without a proper explanatory context and with limited options for reply can sometimes produce results which may in fact be misleading.

Omnibus surveys, ongoing questionnaire surveys of nationally-representative samples, which can include a wide variety of topic areas, depending on the mix of clients at any given time, are used very widely in the sources consulted for this project. Omnibus surveys are particularly useful for simple issues such as consumer choices or, in social topics, where respondents can be assumed to have a broad understanding of the topic area and of the consequences implied by particular response options. Where these conditions cannot be assumed and, as with euthanasia, the issues are potentially complex and far-reaching, the omnibus may not be the ideal tool for providing understanding. This seems to be particularly the case with surveys of the general public, where an understanding of the potential impact of euthanasia/PAS legislation clearly cannot be assumed.

A relatively recent development in United Kingdom research techniques is the use of panels of respondents who are paid for their participation in omnibus surveys. (E.g., 9, 11, 12, 13, 23, 25). This practice tends to produce very high response rates, with hopefully no negative implications for the quality of the response.*

* Practitioners of panel surveys claim that the financial motive and the familiarity with responding to surveys which inclusion within a panel can bring do not interfere with the process of obtaining authentic responses. Set against this is the traditional concern of the United Kingdom market research industry that spontaneity can be eroded by over-exposure to requests for response.

Additionally, other research techniques used in the sources, such as postal or web surveys, may produce some bias in the response to the degree that respondents may effectively be self-selecting. In theory, this can be particularly problematic with a topic such as euthanasia which tends to invite passionate responses from various directions.

This theme, of the limitations of much of the research considered in this report for the purposes of gaining a real understanding of attitudes to euthanasia, is continued in Section 5 Conclusions, where suggestions are made for building upon what is already achieved.

3. GENERAL PUBLIC ATTITUDES TO EUTHANASIA/PAS

3.1 BASIC ATTITUDES TO EUTHANASIA/PAS

It is unfortunate that most of the research carried out into public attitudes to euthanasia lack significant depth and provide relatively one-dimensional results. As explained in Section 2, the research techniques which have mainly been employed have been those with the least capacity to deal with complex and sensitive issues such as euthanasia. In most cases, respondents were given only very limited options for response to relatively simple, direct questions without any context of explanation of what wider implications there might be from a change in the law for individuals and for society.

Nevertheless, it is evident that there is a great deal of sympathy within society, at least for the *concept* of euthanasia, and it seems likely that the level of sympathy has grown in recent years. Evidence for this can be drawn from numerous polls carried out over the last 20-30 years. A small number of them make some attempt to include some of the complexity of the subject within their questioning, but in general the issue of euthanasia is presented very simply. The key questions generally ask respondents their attitude to a change in the law which would favour those who:

- Are terminally ill
- Are in great pain
- Have made it clear that they do not wish to continue living and
- Need help to die

The questions posed and the overall responses are tabulated below, in rough chronological order.

1987 MORI Poll

The earliest survey for which detailed results were available is the 1987 MORI poll conducted as part of the regular MORI omnibus survey and sponsored by two organisations active in the Pro-life movement—*Doctors Who Respect Human Life* and the *Human Rights Society*.

The key question in this survey relating to basic attitudes to euthanasia was Q.2 of a total of 8:

I would like to ask you some questions about euthanasia. By euthanasia I mean when a doctor is allowed by law to terminate the life of a patient.

In Holland some doctors carry out euthanasia when their patients request it, by giving sedatives and injecting muscle relaxants so as to paralyse breathing. Some people have said the law in Britain should be changed so as to allow euthanasia in some circumstances as is done in Holland. Others believe the law should not be changed. Looking at this card, which of these options comes closest to your view?

Results (1808 respondents)

Euthanasia should be made legal in all cases when the patient requests it	23%
Euthanasia should be made legal only when a patient who requests it is suffering from a severe illness and is in a lot of pain	49%
The law should not be changed so as to allow euthanasia	19%
Don't know	9%

The question presents respondents with what might be termed a fairly stark picture of the process of euthanasia “...to paralyse breathing” but nonetheless half the sample were sympathetic to physician-assisted death in circumstances of severe illness and great pain—and almost a quarter appeared to believe in euthanasia “on request”. Only one in five stand out against the idea of legalising euthanasia. MORI comment with apparent justification that the survey as a whole indicates that “public opinion is somewhat more in favour of than opposed to the idea of legalising euthanasia in Britain” (1).

Again, it is important to repeat that even a survey as carefully constructed and objectively analysed as this one is, cannot be viewed as presenting more than a superficial view of public attitudes to euthanasia because of the limitations of the research technique employed. However, the survey has a broader scope than some in that it asks a number of questions relating to the possible implications of legalising euthanasia in terms of the impact on elderly patient attitudes to health care, and the potential role of relatives for patients no longer able to communicate etc.—which are covered separately below.

1984-1995 British Social Attitudes Survey

The *British Social Attitudes Survey* (BSA), from the National Centre for Social Research, is widely acknowledged as an important source of understanding of public attitudes with regard to a range of social, political and moral issues. For many years NatCen has contributed importantly to the development of methodologies and of standards within the field of social research. Unlike standard omnibus surveys, which tend to produce raw data for clients and at best a summary analysis of the main findings, BSA data is expertly analysed and findings are presented within a broad context of the general understanding of trends in public attitudes which is generated by the survey as a whole.

The BSA survey of public attitudes to euthanasia also differs from many others in at least one potentially important aspect—it is not commissioned by any outside organisation with a commitment to one side or other of the euthanasia debate. The funding of this element of BSA by the Nuffield Trust has no implications whatsoever for the objectivity of the coverage.

BSA (1995) claims that there is in the United Kingdom “widespread and increasing support for the legalisation of euthanasia- in certain circumstances”. To the simple question –

Suppose a person has a painful incurable disease. Do you think that doctors should be allowed by law to end the patient’s life, if the patient requests it?

- the overall trend in response is clear:

	1984	1989	1994
	%	%	%
Yes, the law should allow it	75	79	82
No, the law should not allow it	24	20	15
Base	1562	1274	1000

BSA 1995 (fieldwork 1994/report 1995) focused upon euthanasia in greater depth than before and discovered that attitudes towards legalisation are more complex than the single question given above might be taken to suggest. Varying levels of support for euthanasia are expressed, linked to particular circumstances. Support is highest when the case involves an individual not expected to recover consciousness and on a life-support machine (86%) and in the case of an incurable and painful terminal illness, such as cancer (80%). Euthanasia for someone not expected to recover consciousness, but *not* on a life-support machine, reduces to 58% (in these cases, the support of relatives is assumed). 51% support the legalisation of euthanasia for those who become *totally* dependent on others, 44% for a non-painful terminal illness and 42% for a painful illness which is not terminal. Support for legalising euthanasia for any who are simply tired of living drops to 12%.

BSA proffers these findings more as indications of the complexity of the issues, rather than as definitive statements of public opinion. Complex processes of analysis of the survey findings reveal that there is, for example, no significant link between age and attitude to the legalisation of euthanasia, but there is a significant (negative) link with the practice of religion and with general attitudes to life as sacred, such as tend to be derived from religion. The survey concludes that the apparent trend towards the belief that euthanasia should be legalised in certain circumstances is part and parcel of a broad process of secularisation in western society—and as such, seems set to grow. It notes that neither of the “principled” approaches of those for or against legalising euthanasia—liberty of the individual/duty of the state to preserve life—adequately represents the more pragmatic approach taken by most individuals when asked to view the issue on a case by case basis.

1976-1993 NOP for the Voluntary Euthanasia Society

The following question was asked in four surveys within this period:

Some adults say that the law should allow adults to receive medical help to an immediate peaceful death if they suffer from an incurable physical illness that is intolerable to them, provided they have requested such help in writing. Please tell me whether you agree or disagree with this?

A simple “agree/disagree” response is required in the rather emotive context of the contrast drawn between an “intolerable” state of existence and the promise of an “immediate, peaceful, death” through “medical help”. The question is not unfair but it seems to invite agreement more than disagreement. In four omnibus surveys

over a period of 17 years, the question was answered as follows by a nationally representative sample of around 2000 individuals aged 15+:

Year	% For	% Against	% Undecided
1976	69	17	14
1985	72	21	8
1989	75	16	9
1993	79	10	11

For the reasons given earlier, these results cannot be taken purely on “face value”, nevertheless the apparent trend towards agreeing with the *concept* of legalising medical intervention for an assisted death cannot be dismissed, especially as it emerges in other surveys around this time, including the two surveys already quoted.

2002-2004 NOP for the Voluntary Euthanasia Society

More recent NOP omnibus surveys for VES ask the following question.

Do you think that a person who is suffering unbearably from a terminal illness should be allowed by law to receive medical help to die, if that is what they want, or should the law not allow them to receive this medical help to die?

Again, respondents are invited to respond simply *Yes*, *No* or *Don’t Know*. In October 2002, this was the only question asked, but in July 2004, the question was one of seven. In both cases, the sample was significantly smaller than for the previous surveys (1000 and 790, respectively), indicating slightly lower levels of reliability, though this factor lacks significance in the context of the dominant number of respondents agreeing with the (first part of) the question.

Survey Date	% Yes	% No	% Don’t know
October 2002	81	12	7
July 2004	82	11	7

Again, high levels of sympathy are indicated for physician-assisted suicide for the terminally ill who are “suffering unbearably” though, as before, these results provide no guarantee of public understanding in any depth of the issues involved.

Guernsey/Isle of Man 2004

Small sample omnibus research (500 respondents) was held for VES by NOP in Guernsey and Isle of Man at a point that the issue of euthanasia was current within the local parliaments. The key question intended to measure basic attitudes to euthanasia varied slightly in format between the two locations but effectively brought a confirmation that feelings on these islands are roughly similar to those expressed in mainland United Kingdom.

Guernsey

Do you think that a Guernsey resident who is suffering unbearably from a terminal illness should be allowed by Guernsey law to receive medical help to die, if this is what they want, or should the law not allow them to receive this medical help to die?

Yes	77%
No	16%
Don't know	7%

Isle of Man

On the Isle of Man, it is a criminal offence to assist a person to commit suicide. Do you think this law should be changed so that assisting a person to commit suicide is no longer a criminal offence...

Under any circumstances?	7%
When that person is suffering from an incurable disease?	68%
Under no circumstances whatsoever	21%
Don't know	4%

'Straw polls'/reactions to the Diane Pretty case

A number of media polls have been held on the subject of euthanasia, mostly in the wake of the Diane Pretty case. These are less reliable as thermometers of public opinion even than conventional omnibus surveys, mainly because they are based on self-selecting audiences, and tend to use simplistic question formats, often with no response functions beyond Yes/No. Importantly, in relation to the Diane Pretty case, these polls functioned within the emotionally charged context of media coverage of that event. The results have tended to be even more strongly in favour of the legalisation of euthanasia than more conventional polls.

The Voluntary Euthanasia Society have publicised the following findings for 3 polls held between 20th and 26th August 2001:

Teletext poll

We asked you if you back a terminally ill woman's wishes to die without her husband facing prosecution.

Yes	90%
No	10%

Independent on Sunday

Diane Pretty, who suffers from motor neurone disease, began her legal battle last week to establish that her husband will not be prosecuted if he helps her to commit suicide. We asked: should people have the right to die when they choose?

Yes	85%
No	15%
Base	Not given

Sky Interactive Poll

Euthanasia: should it be legalised?

Yes	84.5%
No	15.5%
Base	3563

Heaven and Earth Show, September 26th 2004

A more recent media poll was held by the BBC Religion & Ethics programme *The Heaven and Earth Show*. In the wake of a discussion of the topic, viewers were invited to respond by email, text or phone to the question:

Should assisted suicide be made legal?

Again, only Yes or No answers were sought, with the following results:

Yes	73%
No	27%
Base	Not given

At best, these polls can be said to offer no challenge to a basic assumption in favour of the concept of legalising euthanasia as indicated in the various surveys detailed above. However their real value for gauging public opinion more meaningfully is perhaps best summed up by the series producer for the programme last quoted:

“This is no more than a straw poll, based on random input from viewers .There is no pretence that the sample is scientifically selected or in any way representative of public opinion as a whole”

3.2 PUBLIC ATTITUDES TO EUTHANASIA/PAS: SPECIFIC ISSUES

Various issues linked to attitudes to euthanasia/physician-assisted suicide appear in the findings of specific surveys and any research results of interest for broadening the understanding of public attitudes to the legalisation of euthanasia/PAS are summed up here.

What differentiates those for from those against euthanasia?

In fact few of the surveys are able to throw much authoritative light on the socio-demographic make-up of the two “sides” of the euthanasia debate (as constructed by the general tendency to treat the topic on a simple basis of agreement/disagreement). The best source for providing some commentary upon apparent differences between the two “groups” remains the *British Social Attitudes* survey of 1994/95. This suggests that, at least at that time, opponents of the concept of euthanasia were inclined to be found among people who, relative to those in favour of euthanasia, tend to be:

- Regular churchgoers
- Ethnically mixed – those most in favour tend to be mainly white
- Scottish (the only regional bias to emerge)
- Able-bodied
- Less educationally qualified
- More committed to “sanctity of life” issues—anti-abortion/suicide/capital punishment (the last is the least sure)

Importantly, there appeared to be little or no link with age, gender or social class, nor with party political identity.

Attitudes of disabled people

There are three sources claiming some insight into attitudes of disabled people to euthanasia—(2), (10), (11). BSA (2) notes that disabled people are more pro-euthanasia than able-bodied people, but that this link is only significant among young disabled people. The link is interpreted in terms of a higher level of sympathy for pain and dependency, gained through personal experience.

A January 2003 survey for the Disability Rights Commission (10) was based on an in-house constructed web poll of 162 individuals, 56% of whom categorised themselves as disabled. The results suggest that disabled people are more concerned (than others are) for disabled people to be protected against discrimination in potentially end-of-life medical treatment—and less concerned (than others are) for euthanasia to be legalised for disabled people. The value of the survey is somewhat circumscribed both by the small size of the sample and the self-selecting nature of the research technique employed.

In November 2004, a YouGov omnibus survey for VES was answered by 2091 respondents, around a quarter of whom categorised themselves as disabled on the basis of a definition drawn from the Disability Discrimination Act*. The results suggest that disabled people support the Assisted Dying for the Terminally Ill Bill as strongly as able-bodied people (80%) and also that, should euthanasia be legalised, they would continue to trust doctors as much as they do at present. Disabled people also appear to believe slightly more strongly than others that the law currently discriminates against terminally ill disabled people who wish to commit suicide but need assistance to do so. The results also suggest that disabled people are slightly more likely than others to believe that the Bill would improve society’s view of disabled people.

* This refers to a mental or physical impairment which has had an adverse effect upon the ability to carry out normal day to day activities, but does not incorporate any concept of degree of adverse effect.

The questions raised in this survey are both complex and sensitive and it can only be repeated that omnibus surveys are probably the least suitable research technique for gaining any depth of understanding of public attitudes to such topics, at least without the benefit of a previous stage of in-depth research to inform both the questioning and the interpretation of the results.

The potential impact of the legalisation of euthanasia.

Issues addressed at one point or another include:

- Attitudes to ‘passive’ euthanasia
- Levels of trust in doctors/the health service
- Impact upon hospice services
- Impact on ‘vulnerable’ patients
- Trust in relatives
- Need to take account of public opinion

Attitudes to ‘passive’ euthanasia

This issue is addressed once only, in a 1999 Capibus omnibus survey for First Do No Harm, a pro-life grouping of doctors. The single question (to 2042 respondents) is fairly emotively expressed and the results show the population to be strongly against the concept of a legal right to withhold food and fluid, but not massively so:

The British Medical Association says that doctors may withhold tube feeding and hydration from patients such as victims of a stroke, who are not dying but might be permanently disabled. This would make them die for lack of fluid. Some other doctors’ groups disagree with the BMA. Do you think doctors should have a legal right to withhold food and fluid?

Should have a legal right	30%
Should not have a legal right	56%
Don’t know	11%

Trust in doctors

Overall, trust in doctors appears likely to be marginally undermined by the legalisation of euthanasia, as exemplified by the responses to a direct question asked by VES in a YouGov omnibus survey (1574 respondents) of October 2004:

If the law were changed to allow, within strict guidelines, a terminally ill adult who was suffering unbearably to ask for and receive medication to end their life at a time of their choosing from their doctor, overall would you trust doctors...

More	9%
The same	70%
Less	9%
Don’t know	11%

A similar question concerning **nurses** suggested a similarly high level of trust but one which was slightly more likely to be eroded in the event of legalised euthanasia.

87% of the sample of 500 inhabitants of Guernsey (5) felt they would *still trust their doctor* if assisted dying were made legal. The latest VES/YouGov survey (11) produced the following result:

If this Bill were to become law, would you trust your doctor...

More	6%
Same amount	77%
Less	9%
Don't know	8%

Perhaps unsurprisingly, in one survey (7), doctors are the lead choice for assistance to die legally, though not overwhelmingly so:

If it were legal to ask for and receive assistance to die, who would you ask to help you?

Doctor	55%
Nurse	2%
Relative	19%
Friend	9%
None of these	8%
Don't know	7%

There is some evidence (1) (in 1987) of a general reluctance to *oblige* doctors to carry out (legalised) euthanasia as part of their contract—only 31% of 902 respondents felt they should, against 52% who disagreed.

Fear of hospitals

The last quoted survey also suggested that many people (60%) feel that elderly people in particular might be more nervous of going into hospital if euthanasia were legalised.

Living wills

The issue of living wills is addressed only in the British Social Attitudes survey (1) and is mentioned here as it is contingent to attitudes to doctors, in the case of euthanasia being legalised. The survey showed broad approval for the concept of living wills and 1:4 respondents felt that doctors should be allowed to act on them and end a patient's life if so requested. However, a somewhat lower proportion (62%) felt that doctors should be *obliged* to do so.

Impact on hospice services

This issue was raised only in the Isle of Man where response appears to suggest that 3:4 do not think that a change in the law on euthanasia will damage the work

currently done by the Isle of Man Hospice. However, not inconsiderable minorities, particularly of older people, feel either that it might—16/20% (total/55+) or that they cannot judge (11/16%).

Impact on 'vulnerable' people

The 1987 MORI survey (1) suggests that a large majority (71% – only 12% disagreeing) believe that people permanently dependent on others for medical or nursing care might request euthanasia in order not to be a burden on others. The question (3c) appears to hypothesise euthanasia on request but nevertheless the weight of agreement seems interesting.

Trust in relatives

The same survey (1) suggests that there is a fairly widespread disinclination to trust next of kin to request euthanasia for patients who are unable to communicate—31% believed this should be permitted, but 47% did not.

Consulting the public

Only in the two off-shore surveys (Isle of Man and Guernsey (5,6)) is the issue raised of *how* agreement should be reached about changing the law on euthanasia. It may be that the results of this question are mainly pertinent to the two locations, but the suggestion is introduced that the issue of euthanasia legislation requires an important level of input from the general public and not just from politicians. In both cases, around 4:5 respondents chose a referendum as a means of deciding whether assisted dying should be made legal—against a decision being achieved *by politicians in the normal way any Bill is voted on*.

Action in the absence of new legislation

The latest NOP/VES survey (7, July 2004) suggests that an important proportion of the population might be prepared to break the law to help someone else to die (47%) or would like someone else to help them to do so (51%), in the case of a terminal illness and unbearable suffering. A similar proportion (50%) felt that in these circumstances they would consider going abroad to receive assistance to die, to a country where this was legal—a proportion which was replicated in Guernsey.

However, in the case of a change in the law, inhabitants of the Isle of Man were fairly strongly against allowing the island to become a refuge for those from countries where euthanasia is illegal.

Is euthanasia currently practised – illegally?

This question has not been asked of the general public on mainland United Kingdom but when it was raised in Guernsey and the Isle of Man (5) (6) the results appear to demonstrate a widespread belief that euthanasia is already a fact of life.

Do you think that euthanasia is already sometimes practised, on terminally ill patients in the final stages of illness, as an act of mercy?

	Guernsey %	Isle of Man %
Yes	68	71
No	12	11
Don't know	21	17

4. VIEWS OF POLITICIANS

Two surveys of Members of Parliament, 1995 and 2004, (12, 13) both suggest that attitudes to the legalisation of euthanasia among MPs is the reverse of what appears to be the case with the general public.

In 1995, 70% of MPs opposed (and 27% supported) the principle of voluntary euthanasia, where a patient is terminally ill, subject to detailed legislative safeguards.

In 2004, 79% opposed and only 21% supported the principle of *a Bill to legalise voluntary euthanasia*. In the earlier survey, Labour MPs were rather more supportive of the proposition than their Conservative colleagues, but both parties were similar in attitude in the second survey.

Both surveys were said to produce results largely similar to those of surveys carried out in 1992 and 1994.

The earlier survey was based on telephone interviews with 151 MPs and in 2004, 100 MPs emailed their responses. In both cases, the sample represented the composition of the House of Commons in terms of party affiliation. The first survey was carried out for the *House Magazine* and the more recent one for the Pro-life Alliance.

The reasons for the apparent gulf in attitude between MPs and those they represent can only be speculated upon at this point, a process which lies beyond the capacity of this report. However, an obvious factor of difference could be that MPs, by definition, are more accustomed than most to taking into account the implications for society as a whole of proposed legal reforms, as a separate issue to their personal feelings on the subject.

5. VIEWS FROM THE HEALTH SECTOR

5.1 DOCTORS' VIEWS OF EUTHANASIA/PAS

In general

The views of the medical profession are expressed through a number of surveys which, as with the surveys of the general public considered in Section 3, vary importantly in quality and in scope. However, the overall picture of doctors' attitudes to euthanasia is more complex than that of the general public. At the same time, the data generally enjoys a higher level of credibility, on the assumption that medical practitioners can be assumed to have at least some direct experience of end-of-life conditions and therefore to be able to answer questions more meaningfully on this basis than others. In this sense, the review of medical feelings

about euthanasia is a more straightforward undertaking than that of the general public.

Euthanasia is clearly a subject which presents very many doctors with profound professional and personal dilemmas and overall tends to split the profession between those more and less generally in favour of a change in the law. It seems likely that medical professionals view the issue of the legalisation of euthanasia as less straightforward than the lay public as a whole because of their direct experience of working with patients and there is *some* evidence to suggest that the closer the experience of end-of-life patients, the less sure professionals are about the prospect of a change of the law in favour of euthanasia. Some of the evidence also suggests that, over time, doctors may have become generally less favourable to the concept of legal reform.

Significant differences exist in the quality of the available research information—which ranges from rapid ‘dip-stick’ media-sponsored surveys of the profession through to university-based academic studies and inevitably includes an important number of studies commissioned by organisations with a dedicated interest in the concept of a change in the law related to euthanasia. The evidence is therefore best considered on a piecemeal basis, with some attempt at chronology.

1987: NOP telephone survey of 301 GPs for Voluntary Euthanasia Society. (14)

The sample is small but was selected to ‘broadly represent’ all NHS GPs throughout Britain, excluding vocational trainees.

The results of this survey appear to typify the dilemma of euthanasia for medical professionals—and the contrast with lay public opinion.

59% of the sample disagreed with the concept of changing the law in favour of voluntary euthanasia – 39% disagreed ‘strongly’. The proportion in favour of change totalled 30%, only one third of these agreeing ‘strongly’. 9% of the sample claimed to hold ‘mixed views’.

NOP pointed to the contrast with a recent (1985) study of the public (sample 1712) which asked the identical question* and in which 72% of respondents declared themselves in favour of the suggested change.

The dilemma of euthanasia, for doctors, is perhaps also evident in the difference between attitudes to the *concept* of euthanasia and what doctors might do in practice, were the law to change.

At the moment, euthanasia is illegal. Suppose the law was changed to permit voluntary euthanasia and there was a patient on your list whose case you knew well, who suffered from an incurable physical illness that was intolerable to them. If that patient made a signed request that you end his/her life, would you consider doing so or not?

Yes, consider	Perhaps possibly	No – would not
35%	10%	53%

Base 301

* Some people say that the law should allow adults to receive medical help to an immediate peaceful death if they suffer from an incurable physical illness that is intolerable to them, provided they have previously requested such help in writing. Do you agree or disagree with this?

Clearly, rather more GPs were prepared to consider euthanasia in certain circumstances (45%) than had stated that they were in favour of the concept of euthanasia (30%).

Male GPs appeared to be more favourable to the concept of legalised euthanasia than females and in general, attitudes tended to correlate negatively with age, but the small base of the study limits confidence in this level of analysis.

1993: Attitudes among NHS doctors to requests for euthanasia. Ward & Tate, Dept of Anatomy, Cambridge University (15)

This survey was based on anonymous postal responses from 312 GPs and hospital consultants (in roughly equal proportions) within one area of England. The intention was to explore NHS doctors' attitudes to 'competent' patients' requests for euthanasia and to estimate the proportion of doctors who have taken active steps to hasten a patient's death. The base of the sample tends to vary as not all respondents answered each question. It is an important study, apparently carried out with sensitivity and a high level of concern for objectivity and for methodological rigour within the bounds of the *relatively* small sample.

The key findings are that:

- 60% of doctors had been asked at some point by a patient to hasten their death—64% of GPs and 52% of consultants
- 51% of GPs and 36% of consultants had been asked to provide *active* euthanasia, as opposed to *passive* euthanasia by withholding or withdrawing treatment
- 1:3 of a sub-sample of 119 doctors (of which 83 were GPs) had taken active steps to bring about the death of a patient. The research suggests that, for whatever reason, GPs are more inclined than hospital consultants to comply with a request for *active* euthanasia
- The great bulk of doctors (88% of GPs and 95% of consultants) stated that in some circumstances they would be prepared to practice *passive* euthanasia*

In this context, views of whether the United Kingdom law on euthanasia should be changed to become similar to the Dutch law are perhaps not surprising. Significantly more agreed than disagreed with the proposition, as follows:

In the Netherlands, doctors are now virtually certain to avoid prosecution if they end the life of a patient, provided:

- This is the patient's well-considered wish
- The patient has an irreversible condition causing protracted physical or mental suffering which he or she finds unbearable
- There is no reasonable alternative (from the patient's point of view) to alleviate the suffering
- The doctor has consulted another professional who agrees with his or her judgement

* Sometimes I would be prepared to withdraw or withhold a course of treatment from a terminally ill patient, knowing the treatment might prolong the patient's life

Do you think a similar situation should exist in Britain?

Response	% GPs (Base 169)	% Consultants (Base 140)	% Total (Base 309)
Strongly agree	15	15	15
Agree	33	31	32
Undecided	23	15	19
Disagree	19	27	23
Strongly disagree	10	11	10

46% of this sample (51% of GPs and 40% of consultants) stated that they would personally be prepared to consider practising euthanasia, if asked to by competent patients—a total of 32% would not.

Attitudes to euthanasia were consistent throughout the responses to the specific questions on the subject, showing that doctors either supported euthanasia or rejected it. However, practice could sometimes be at variance with belief (most notably among those with religious beliefs, who tended to reject the concept of legalising euthanasia but had sometimes practised active euthanasia)—implying, in the words of the study, ‘painful personal dilemmas’ experienced by some doctors.

Addendum: GPs v Hospital Specialists

The suggestion running through the results of the study quoted above, that GPs tend to be more open than hospital consultants to changing the law in favour of euthanasia, appears to receive some confirmation from a study for VES of around 2000, only some details of which are clear (22). This study concluded from a sample of 554 GPs and 398 hospital specialists that GPs are significantly more in favour of a change in the law than hospital specialists (Oregon provided the role model for change on this occasion) and more willing to consider practicing active euthanasia.

1995: Doctor magazine omnibus survey of 2150 doctors, mix of GPs and hospital specialists. (17)

This survey continued the suggestion that the medical profession was split in its attitude to legalising euthanasia. Key findings were:

- 44% supported legal reform against 53% who rejected it
- Within the previous year, 57% of doctors had been asked by patients and sometimes relatives/friends of patients to practice one form or other of euthanasia
- If active euthanasia were legal, 43% – slightly more GPs than hospital doctors—would consider it
- Around 80% of doctors (including religious believers) saw passive euthanasia as an accepted part of medical practice

1996: BMA News Review survey of 750 general practitioners (18)

Overall, the results appear roughly similar in stance to previous studies of GPs, though there are differences of detail:

- 46% of GPs supported and 44% rejected legal reform
- If it were legal, 37% would consider active euthanasia for terminally ill patients—only a small number admitted to having practiced it
- 92% felt that passive euthanasia could sometimes be justified
- 75% felt they would respect a refusal of treatment required by a living will

1996: Survey of Medical Practitioners' Attitudes towards Physician-Assisted Suicide. Study by Professor MacLean on basis of omnibus survey of 1000 respondents, mainly a range of doctors but including 180 pharmacists (19)

Key findings were:

- 1:5 believed suicide was never justifiable and 1:4 felt it was justified simply by wishing it. 1:2 felt suicide was justifiable on the basis of a terminal condition and/or extreme physical/mental suffering
- 65% were in favour of a change in the law, including 10% who believed in 'euthanasia on demand' i.e. no other conditions. Again, the bulk of respondents stressed the importance of patients having a terminal condition and/or experiencing extreme physical/mental suffering
- Significantly less practitioners would be willing to assist suicide if this were legal—53% in total, including 7% requiring only the wish of the patient
- 28% had been asked to provide the means for patients to kill themselves
- 4% admitted to having provided the means for patients to kill themselves and 93% claimed never to have done so. However, 12% claimed to know other health professionals who had assisted a patient to kill themselves

Importantly, this study distinguishes physician-assisted suicide from euthanasia—43% were in agreement with the former, in comparison to only 19% in favour of active euthanasia. This was interpreted in the commentary as possibly reflecting a reluctance to take full responsibility for the implications of euthanasia.

Also, reasons given for and against PAS were prioritised for salience by the respondents. The top reasons in favour of PAS were:

- *The duty of doctors to relieve suffering (60%)*
- *People suffer intolerable and incurable conditions (59%)*

Principal reasons against PAS were:

- *Problems in judging when suffering is sufficient to justify PAS (53%)*
- *Many who feel suicidal later regret those feelings (50%)*
- *It is the duty of doctors to preserve life, not end it (32%)*

1998: Sunday Times survey of 300 GPs (20)

The findings of this rapid media survey are interesting in that levels of involvement in active euthanasia are distinguished. Full details of the study are not available. Key findings, as presented by the paper, were:

- 1:7 of the respondents had ‘helped patients to die’ at their request
- 60% felt that they should be allowed to administer large amounts of painkillers even if this shortens life
- 18% felt they should be able to prescribe lethal medication for patients to commit suicide

1998: *National Survey of Psychiatrists’ attitudes to euthanasia*, University Department of Psychiatry, Royal Free Hospital, London. Postal questionnaire survey of 322 senior psychiatrists. (26)

Only brief details are available for this study, the first among United Kingdom psychiatrists to explore attitudes to assisted suicide. Attitudes tended to be slightly more conservative than those found among other medical professionals up to this point. The key findings included the following:

- 38% of psychiatrists believed euthanasia should be legalised—against 44% who did not
- 35% were willing to assess psychological suitability for euthanasia (against 47% who preferred not to)
- 86% accepted that suicide can be rational; however, 2:3 felt that a psychiatric assessment should be made of all individuals requesting euthanasia
- 83% felt that passive euthanasia could be justified, but only 29% felt this of voluntary active euthanasia and 40% of assisted suicide—only 1:5 stated a willingness to assist suicide
- Living wills were acceptable to 36% and not acceptable to 40% as a basis for assisting non-competent patients to commit suicide.

1999: TNS Omnimed survey of 104 GPs, sponsor unknown. (21)

This survey was very limited in scope and relatively few details are given. The findings as given include the following:

- 2:3 favour euthanasia in certain situations and believe this to be generally the case with their colleagues
- 1:3 are ‘very opposed’ to euthanasia under any circumstance
- 1:2 had discussed the subject of euthanasia with colleagues
- 3:5 ‘knew of’ patients who had made living wills
- 2:3 felt that potential legislation into euthanasia should be further investigated

1999: *United Kingdom Geriatricians attitudes to active voluntary euthanasia and physician-assisted death*. Universities of Sheffield and Charleston, South Carolina. (27) 333 respondents in a postal survey of all United Kingdom geriatricians (45% response)

This study was carried out by the Academic Palliative Medicine Unit of the Sheffield Institute for Studies on Ageing and formed part of an ongoing longitudinal study based on the Department of Sociology at Charleston University.

The study was said to be neutral in orientation, though an underlying concern was to respond to what was seen as a ‘push’ towards euthanasia in society.

In fact, the responses made in this study are in some contrast to the general thrust of other medical opinions up to this point. Key findings are that United Kingdom geriatricians, as represented by the sample of 45% of their number, tend to believe that:

- Active euthanasia: Administering an overdose primarily intended to end a patient’s life can never be justified ethically (80%)
- However, 23% felt it should be legal in some circumstances
- PAS through prescription or counselling can never be justified ethically (68%)—24% felt, however, that it should be legal in some circumstances
- Only 12% and 13% respectively felt that they would personally practice active euthanasia or PAS in some circumstances

The study offers no explanation for the contrast between these views and the general trend of medical feeling about these topics. It may be that respondents are influenced by their high level of familiarity with patients in end-of-life situations. The principal reasons given for not wanting euthanasia/PAS to be legalised were stated as:

- A belief that legalisation might put pressure on vulnerable patients to request euthanasia/PAS (84%)
- A fear that the social process of dying and grieving may become undermined (53%)

Two thirds of the small minority who favoured legalisation of euthanasia/PAS did so as specific legal guidelines ‘might help prevent abuses’. Other majority reasons given by this small group included:

- Respect for patient self-determination
- To prevent an unacceptable deterioration of the quality of life

The study did not include an exploration of attitudes to passive euthanasia.

2003: *Hospital Doctor* auto-response survey of 3000 doctors.

Only bare details are available of this readership-based study carried out in association with the Nuffield Trust. The study claims that doctors’ attitudes are hardening against the legalisation of euthanasia, on a basis of a reduction in support noted between this study and a similar study carried out in 1994—38% against 44%.

2003: *Survey on Euthanasia and Assisted Suicide*, Opinion Research Business for Right to Life. (24) An internet omnibus study carried out by Doctors.Net.UK. 986 respondents, 2:3 of whom were GPs and the rest a spread of hospital specialists, with some bias towards psychiatry (13%).

A permanent panel of respondents is regularly invited to answer questions posted on the Doctors.Net web-site. As with the last quoted study, this survey claims that the majority of doctors are not in favour of either euthanasia or assisted suicide. In this respect the key questions were:

As a doctor are you in favour of either of the following?

	Euthanasia %	Assisted Suicide %
Yes	22	25
No	61	60
Don't know	14	13

If these actions were made legal, would you be prepared to perform any of the following?

	Euthanasia %	Assisted Suicide %
Yes	23	26
No	76	74
No reply	1	0

Pressure from relatives, beneficiaries and medical and nursing colleagues

If these actions were made legal, would you be confident that you would be able to exercise your judgement free from pressure from:

- *Relatives?*
- *Beneficiaries?*
- *Medical and nursing colleagues?*

Freedom from pressure from:	Relatives	Beneficiaries	Medical/nursing colleagues
Yes>%	29	58	28
No>%	47	29	43
Don't know>%	24	12	28

Doctors interviewed showed high levels of concern about the potential influence on their freedom to exercise their judgement of relatives and colleagues in any new legalised situation. The sample as a whole were not very concerned that consideration of NHS resources would influence their judgement. Those willing to carry out euthanasia or assisted suicide were generally less concerned about these sorts of pressures.

Most of the total sample (59%) felt that the BMA should not change its opposition to the legalisation of euthanasia and assisted suicide though, unsurprisingly, the majority (75%) of those willing to practise them would counsel change. A similar divergence of opinion was evident on the issue of whether safe bounds can be set on euthanasia—only 56% of the total sample believed so, against 80% of the stated minority.

Two thirds of the sample were confident that they would be able to detect whether a request for assisted suicide was part of a depressive illness, suggesting that this could be an area of some concern for an important minority.

A high proportion of the total sample felt that increased resources for hospice (66%) and geriatric (55%) care would be likely to reduce the pressure towards the legalisation of euthanasia/assisted suicide.

Conclusion

This study suggests that medical opinion is now less split than a few years ago on the issue of legalising euthanasia and assisted suicide and that concerns about the potential implications of legalisation may be growing.

2003/4: Medix web-based omnibus surveys for Voluntary Euthanasia Society (January 2003 and August 2004)1000 respondents

These studies are carried out among a permanent panel of doctors who are remunerated for responding to questionnaires which are posted on the web-site.

The two studies, roughly a year and a half apart have sufficient common elements to be compared. The key findings are summarised below.

- In 2003, 33% of doctors believed the law should be changed in favour of physician-assisted suicide (48% were against and 19% unsure). The direct question was not asked in 2004.
- The results of a question on the circumstances for permitting PAS appearing in both years could be interpreted to suggest a waning of support for the legalisation of PAS, i.e.:

Circumstances for permitting PAS

	2003 %	2004 %
No circumstances	39	42
Terminal illness with uncontrollable physical suffering [*]	55	45
When a terminally ill patient wishes it	26	20
Severe physical suffering, even without terminal illness	22	15
When a patient wishes it	3	2

Similarly, a question about the circumstances for permitting physician-assisted euthanasia, i.e. direct help to die, produced results which could also be interpreted as marking a lessening of support for euthanasia among doctors. The key categories were:

	2003 %	2004 %
No circumstances	44	53
Terminal illness with uncontrollable physical suffering ^α	50	37
When a terminally ill patient wishes it	22	14
When a patient wishes it	2	1

^α In 2004, this was changed to *When a patient is terminally ill with unbearable suffering and is physically unable to commit suicide, e.g. MND*

The 2004 sample appeared to have less experience of patient requests for assisted suicide or euthanasia than the earlier sample, a factor which may throw some light on their generally more conservative approach to the concept of legalising euthanasia.

Have you ever been asked by a patient to assist in their suicide or euthanasia?

	2003 %	2004 %
Yes	40	27
No	57	70

Frequency of assisted suicide/euthanasia

The 2003 survey established that around 80% of doctors thought that both practices are *rare* or *fairly rare*. In 2004, it was established that 45% of doctors believed that some health professionals do sometimes assist the suicide/voluntary euthanasia of their terminally ill patients—an equal proportion could not say.

A separate question in 2004 supported these last findings, suggesting that 1:2 doctors believe that there are circumstances where some health professionals in the United Kingdom currently give pain relief to terminally ill patients with the intention of shortening their life.

Frequency of suicide/suicidal feelings among terminally ill patients

Questions in both years to establish how many patients *with an untreatable and debilitating long-term or terminal illness* (2004 just *terminal illness*) attempt/commit suicide—and (in 2003) what proportion of those attempting suicide worsened their health in the process, achieved little response.

Somewhat similarly, a question in 2003 aimed at measuring the level of seriously ill patient statements of a preference to die rather than live brought results suggesting that for the great bulk of doctors, this is at most, an occasional rather than a common experience.

Safeguards

In 2004, doctors were asked what safeguards should be put in place for terminally ill patients requiring assisted suicide/euthanasia and the doctors prepared to help them. Of the two options offered, the concept of legislation with safeguards and guidelines proved much more attractive than that of a criminal law prohibiting the practices, though over 1:5 were unable to reply.

Influence of religious belief upon attitudes to euthanasia

Some link between religious belief and attitudes to issues around euthanasia was established among the general public, most notably in the *British Social Attitudes* survey. Interestingly, a direct question in the later *Medix* survey for VES asking whether respondents believe that their attitudes on these topics are influenced by religious belief, revealed that this was in fact the case, at least to a small extent, in the judgement of 41% of the 1000 doctors interviewed. This factor too may hold some relevance to the apparent differences in attitudes between the two samples, but unfortunately it was not measured in 2003—nor in any of the other surveys

quoted above which contribute to the sense of a withdrawal of medical profession support for euthanasia.

Summary of doctor attitudes up to the present

The attitudes of doctors to euthanasia are not easy to summarise accurately as different surveys approach the subject in different ways and the nature and value of each exercise must be borne in mind when interpreting the results. However, there seems to be some value in focusing on two key aspects of the debate which are measured more or less directly in most of the surveys which have come to light. These are:

- Attitudes to legal reform in favour of euthanasia/PAS
- Levels of willingness to practice euthanasia/PAS, should it be legalised.

For the purposes of creating a meaningful and helpful summary, the concepts of physician-assisted suicide and physician-assisted euthanasia are mainly not distinguished—attitudes to each tend to be broadly similar. Passive euthanasia, about which there is relatively little debate, is not considered here. References are included to the surveys as listed in the appendix. It was not possible to include all and maintain a satisfactory consistency of meaning.

Attitudes of doctors to the legalisation of euthanasia 1987-2004

Year	Ref.	% For	% Against	Comment
1987	(14)	30	59	Small sample (301)
1993	(15)	47	33	Competent, but small in scale
1995	(17)	44	53	Self-selecting media survey
1996	(18)	46	44	Self-selecting media survey
1996	(19)	65	30	‘Willing to assist suicide, if legal’ Some pharmacists in the sample.
1998	(20)	Not	clear	Small scale media poll – 18% felt they should be able to prescribe lethal medication for suicide legally
1998	(26)	33	41	Psychiatrists only
1999	(21)	66	33	Details unclear, no grey areas allowed for
1999	(27)	23/4	n/a	Geriatricians
2003	(23)	33	48	Self-selecting web poll for VES
2003	(16)	38	n/a	Self-selecting media poll
2003	(24)	22/25	60/61	Self-selecting web survey for Right to Life
2004	(25)	Not	comparable	Self-selecting web poll for VES. Generally more conservative than similar poll in 2003 (23)

5.2 ATTITUDES OF OTHER HEALTH SECTOR PROFESSIONALS TO EUTHANASIA/PAS

Nurses

Auto-response readership surveys were held by *Nursing Times* in 1988 and 2003, achieving 1000 and 2700 responses respectively.

The results for 1988 are not easily related to the main theme of this report and mainly communicate a high level of sympathy for patients with pain and a sense of division in the profession concerning willingness to be involved in administering drugs which will kill a terminally ill patient at their request—44% were willing and 55% declared themselves unwilling.

The 2003 survey relates more readily to the theme of this report but few details have been made available. The main claim of the journal is that “two thirds” of the nurses responding to the questionnaire believed that euthanasia should be legalised—and that 31% believed that nurses should be allowed to assist in the suicide of patients.

Pharmacists

A 1998 postal questionnaire survey of 169 pharmacists by the Universities of Bristol and Manchester mainly explored pharmacists’ attitudes to becoming involved in physician-assisted suicide through dispensing the required drugs. Key findings are:

- 70% believe that it is a patient’s right to choose to die
- 57% agree a patient should be able to involve his/her doctor in the process
- 45% believed that it was right for such patients to use prescription medicines for suicide
- 54% felt it is appropriate for pharmacists to refuse to dispense a prescription to be used in PAS (89% felt the conscience clause of the RPSGB code of ethics should incorporate this)—but 49% said they would willingly dispense such a prescription (24% would not)
- 44% felt the law should be changed to allow for PAS 33% disagreed) and 52% that legislative change is required primarily to regulate PAS

Palliative Care Staff

The findings of 2004 qualitative research among a range of palliative care staff have been submitted separately to the Select Committee by *Help the Hospices*.

The research is small in scale but appears adequate to provide a useful commentary upon the views of euthanasia held by those working in the sector. It is not easily related to the main theme of this report, despite attempts to express the findings through quantification. The great value of the research appears to be in throwing some light upon the implications of a change in the law in favour of euthanasia for end-of-life patients and for those in their care. It brings a closeness to the ‘reality’ of euthanasia which is beyond the reach of quantitative research.

Despite evident and well-informed sympathy for the pain felt by terminally ill patients, it is clear that the introduction of legalised euthanasia would be very

contentious within the hospice movement. Legalised euthanasia was seen as capable of changing the ethos of hospice care for the worse and of eroding the relationship of trust between physicians, carers and patients. It was also seen as in danger of serving to reduce the focus on hospice/palliative care. For many reasons, it was felt to be difficult to accurately assess a terminal patient's psychological condition and fitness for choosing euthanasia. Some were clearly open to the concept of euthanasia, but it was also clear that many professionals/carers would have ethical and other personal difficulties related to any requirement for involvement in the practice of euthanasia.

6. CONCLUSIONS OF THE DESK RESEARCH

The research carried out up to this point into public and health sector attitudes to the legalisation of euthanasia is limited in value and cannot be accepted at face value as an authentic account of opinion within the United Kingdom. The subject matter is extremely complex and sensitive and therefore very challenging for any attempting to gain a meaningful understanding of opinion.

Public opinion

This is particularly the case with regard to the attitudes of the general public, whose real views on euthanasia are clearly obscured by a lack of information on the subject and by the lack of opportunity to reflect in an informed way upon the implications of any change in the law for themselves and for society. The levels of agreement/disagreement with the concept of euthanasia which the numerous polls record are effectively built on what might be termed a "knee-jerk" reaction to the simple options provided by these polls and do not form a very useful guide to public opinion as support for legislative change.

Nevertheless, the apparent groundswell in public agreement with the concept of euthanasia registered by the various sources cannot be dismissed and it is evident that there is much sympathy at a personal level for the concept of legally releasing those wishing to die from their pain and those willing to help them from legal consequences. However, if the decisions of the Committee are to take authentic account of properly informed public opinion, a significant investment in more appropriate forms of research is undoubtedly required.

Deliberative research

Latterly, government is accustomed to exploring public opinion on difficult and complex topics through various forms of deliberative research. Recent examples include studies of public attitudes to the management of radioactive waste and to the commercialisation of GM crops, carried out at part of an attempt at public consultation on these complex and difficult subjects. Various techniques exist for this, including deliberative polls, citizen juries, reconvened focus groups etc., each aimed at achieving an authentic response such as is only available on a basis of information.

Only research of this sort is capable of providing a satisfactory understanding of public attitudes to the legalisation of euthanasia/PAS and of quantifying it meaningfully.

Health Sector

As remarked in the body of this report, health sector professionals tend by definition to be better informed about the context and potential implications of the legalisation of euthanasia, but here again most research is superficial in coverage and only a few attempts have been made to understand the basis of the opinions of doctors and others, which, from the data, appear to vary in different directions over time. Here too, some fresh, impartial research, again of a deliberative nature, is required in order to gain a full and useful understanding of health sector views.

ANNEX 1: RESEARCH SOURCES

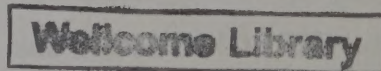
1. *MORI omnibus poll December 1987*, for Doctors Who Respect Human Life/Human Rights Society. 4 questions to 1808 adult respondents nationwide.
2. *British Social Attitudes 1994/95*, National Centre for Social Research. The BSA has been run annually since 1983 to measure the attitudes, values and beliefs of the British public, covering an extensive number of complex social, political and moral issues. Euthanasia was included in 1984, 1989 and then in much greater depth in 1994/95, based then on a sample of 1234 adults. The subject is likely to be included in BSA 2005 also.
3. *1999 Capibus omnibus*, 2042 respondents, single question on doctors' right to withhold food/fluid, for First Do No Harm, an organisation of doctors concerned about a perceived climate in favour of euthanasia
4. *NOP omnibus survey of UK*, October 2002 for Voluntary Euthanasia Society. Single question, 1000 respondents aged 18+.
5. *NOP omnibus Survey of Guernsey 2004*, for Voluntary Euthanasia Society. 5 questions, sample of 500 adults.
6. *NOP omnibus survey of Isle of Man*, 2004 for Voluntary Euthanasia Society. 5 questions, sample of 500 adults.
7. *NOP omnibus survey of UK*, July 2004, for Voluntary Euthanasia Society. 7 questions, sample of 790 aged 18+.
8. *BBC Heaven and Earth programme*, September 2004. A single question put to viewers for immediate email/text/phone response.
9. *YouGov omnibus survey of UK* October 2004, for Voluntary Euthanasia Society. 2 questions to sample of 1584 adults.
10. *Disability Rights Commission Web Poll* January 2003. 4 questions, 162 respondents, 56% of whom were disabled.
11. *YouGov omnibus survey* of November 2004. 2072 respondents, focus on disability issues.
12. *Harris Political Research Unit Parliamentary Panel/The House Magazine*. Poll of 151 MPs broadly representative of the party composition of the House of Commons, July 1995.
13. *Communicate Research Parliamentary Panel*, September 2004, for ProLife Alliance. A web poll of 100 MPs broadly representative of the House of Commons in party terms.
14. *NOP telephone survey for VES* of 301 GPs, drawn from Medical Direct Mail Organisation mailing list 1987. Two questions to measure support for euthanasia.

15. *Attitudes among NHS doctors to requests for euthanasia*, 1993. Ward & Tate, Department of Anatomy, Cambridge University. 312 postal questionnaires from a mix of GPs and a broad range of hospital doctors in one (unstated) area of England.
16. *Hospital Doctor* survey of 3000 doctors, funded by Nuffield Trust 2003, repeat of similar study carried out in 1994.
17. *Doctor* survey of 2150 GPs and hospital doctors nationwide 1995.
18. *BMA News Review* survey of 750 doctors 1996.
19. *Survey of Medical Practitioners' attitudes towards physician assisted suicide* 1996. Omnibus by System Three (Scotland) for Professor Sheila MacLean, Medical Law Unit, University of Glasgow. Formed basis of book by Sheila MacLean 'Sometimes a small victory'.
20. *Sunday Times* survey of 300 doctors, November 1998.
21. *TNS Omnimed* face-to-face questionnaire survey of 104 GPs October 1999 for BMA.
22. *Differences in attitudes towards physician-assisted suicide between GPs and hospital specialists*. Date uncertain—around 2000—4-question survey of 1025 doctors for VES.
23. *Assisted suicide and euthanasia*, Medix web survey of 1002 doctors, January 2003, for VES.
24. *Survey on Euthanasia and Assisted Suicide*, omnibus survey of 986 doctors by Opinion Research Business for Right to Life, April 2003.
25. *Physician-assisted suicide and euthanasia*, Medix web survey of 1000 doctors, August 2004, for VES.
26. *National survey of United Kingdom psychiatrists' attitudes to euthanasia*, 1998, Shah, Warner, Blizzard, King, University Department of Psychiatry, Royal Free Hospital, London. Postal questionnaire survey of 322 senior psychiatrists.
27. *United Kingdom geriatricians' attitudes to active voluntary euthanasia and physician-assisted death*. 1999. D. Clark, G. Dickenson et al, Sheffield Institute for Studies on Ageing, Academic Palliative Medicine Unit, University of Sheffield; Dept of Sociology, University of Charleston, South Carolina. Postal questionnaire responses from 333 consultant geriatricians (from national total of 742).
28. *British community pharmacists' views of physician-assisted suicide*. Hanlon, Weiss, Rees, Universities of Bristol and Manchester 2000, reported in *Journal of Medical Ethics*, 2000/26/pp363-369. Postal survey of 179 full-time community pharmacists.
29. *Nursing Times* readership surveys, 1988 and 2003 (1000 and 2700 responses, respectively).
30. *Help the Hospices/Clear Thinking Consultancy*. Research among palliative care staff, 2004. Small-scale qualitative research among a range of staff—focus groups with 62 professionals drawn from 29 independent hospices.

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